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THE DIAGNOSIS IS ANENCEPHALY AND THE PARENTS ASK ABOUT ORGAN DONATION: NOW WHAT? A GUIDE FOR HOSPITAL COUNSEL AND ETHICS COMMITTEES

JENNIFER S. BARD*

PROLOGUE: CASE STUDY—THE MS¹

After a period of infertility treatments, Mr. and Mrs. M learned that they were going to have triplets. Mrs. M, shortly thereafter, developed a fear that something was wrong with one of the babies whom she had named Avery. An ultrasound, at seventeen weeks, confirmed Mrs. M's fear. Avery was missing her upper skull. She had anencephaly.² After telling the Ms the result of the ultrasound, the maternal-fetal medicine doctor informed the Ms

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1. This is a report of a case occurring recently at a university medical center.

2. An infant with anencephaly is born without those portions of the brain that create consciousness. See The Medical Task Force on Anencephaly, *The Infant with Anencephaly*, 322 NEW ENG. J. MED. 669, 669 (1990) [hereinafter Task Force]. The defect occurs early in the first month of fetal development when the neural tube, which forms the brain, fails to close completely. See *id.* In common with many medical conditions, there is a range of physical findings that may be labeled anencephaly. This range includes infants born without any brain and those infants born without significant portions of their brain. See *id.* Most infants born with this condition die soon after birth since they lack even the autonomic brain stem function that keeps the heart beating. See *id.* at 671. Pictures detailing the condition of anencephaly can be found in *Pottor's Atlas of Fetal and Infant Pathology*. See ENID GILBERT-BARNES, POTTOR'S ATLAS OF FETAL AND INFANT PATHOLOGY 246-47 (1998). For more information on anencephaly, consult the world wide web; one interesting site is that of the Anencephaly Support Foundation. See *Anencephaly Support Foundation* (visited Apr. 5, 1999) <<http://www.asfhelp.com>>.

about selective reduction.³ He cautioned them, however, that reducing the anencephalic fetus could potentially create a risk of aborting the two healthy fetuses. The Ms did not want to take this risk. Instead, they tracked Baby Avery's growth throughout the pregnancy.

Soon after learning that Baby Avery was likely to survive birth but die shortly thereafter, the Ms thought of organ donation. Mrs. M's mother was critically ill with lung disease and was on the waiting list for a lung transplant. Around the same time, Mr. M remembered that Mickey Mantle was in the news for receiving a liver transplant after only three days on the waiting list. He also recalled David Crosby's receipt of a liver transplant. Mrs. M's mother, however, did not get a transplant and died before the triplets were born. Mrs. M was too ill to attend the funeral. "We felt," said Mr. M, "that she couldn't get [the transplant] because of who she was. A regular person had a harder time."

The Ms raised the issue of organ donation with their obstetrician. Shortly afterward, the obstetrician telephoned the local hospital's transplant team to refer the Ms. One of the transplant coordinators contacted the Ms and was initially positive about the possibility of using Baby Avery's heart as a donor organ. The Ms' understanding of their conversation with the transplant coordinator was that the transplant coordinator "would send a [transplant] team over" when the babies were born. "We felt good." Knowing that Baby Avery could be an organ donor gave the Ms "a little peace of mind." During the pregnancy, Mr. and Mrs. M met a mother whose child was in need of a donor heart. While they knew Baby Avery's heart would not go to that particular child, it made them feel better to believe that a child who needed a heart would benefit from Baby Avery's short life.

Around the same time, the maternal-fetal medicine service first informed the neonatology service of the Ms' situation. It was the first the neonatologists had heard of the imminent arrival of an anencephalic triplet. The neonatologists also learned that the Ms wanted Baby Avery to be an organ donor and that the Ms believed that the transplant team was offering to harvest the organs as soon as the babies were born.

3. This is a procedure in which a needle is inserted into the heart of a fetus, in this case the anencephalic triplet, thus killing it. See Judith F. Darr, *Selective Reduction of Multiple Pregnancy: Lifeboat Ethics in the Womb*, 25 U.C. DAVIS L. REV. 773, 779-80 (1992).

The neonatologists, however, were surprised by this information. They discussed the issue of harvesting the organs shortly after the babies' birth among themselves and then with the hospital's legal counsel; the conclusion was that there was no legal precedent for using an anencephalic infant as an organ donor. The neonatologists also knew, due to a written policy statement, that the consulting neurologist's opinion was that an anencephalic infant was not brain dead, and therefore, was not a candidate for organ donation. At approximately the same time, the transplant team also began to realize that there were serious barriers to harvesting organs from an anencephalic infant. According to the Ms, based on the attitude of the obstetricians and what they were hearing from the transplant team, they began to realize that Baby Avery could not be an organ donor. Mrs. M described the obstetrician as "passive" whenever the idea was raised. The obstetrician, however, disagreed with this perception; he felt that he supported the Ms' decision to donate their baby's organs, but that the harvesting could not be done given the current state of legal and medical practice. Mrs. M remembers specifically, at some point before the birth, being told by the hospital's transplant team that the team could not do the retrieval.

Nevertheless, the Ms remained hopeful that something might be able to be arranged once the babies were born. At thirty-four weeks, on November 10, 1995, Mrs. M went to the obstetrician for a routine ultrasound. The obstetrician determined that one of the two healthy triplets had stopped growing. It was time to deliver the babies by caesarean section. Mrs. M's first reaction at hearing that she was going to give birth to the triplets was relief. She was very uncomfortable with "three sets of arms and legs" pushing against her. Almost immediately though, she saddened. "I didn't want them to take [the triplets] because it would mean that [Baby Avery] would die."

The neonatologist met the Ms for the first time that afternoon and was the first person to tell them definitively that Baby Avery could not be an organ donor. The Ms were disappointed. One of their first reactions was to ask whether Baby Avery could donate organs for the other two triplets if necessary. After explaining that the other two triplets would not need organ donations, the Ms were again told that Baby Avery could not be an organ donor. According to the neonatologist, the Ms had "been led to believe [organ donation] was a possibility when it wasn't."

Baby Avery was delivered on November 10, 1995, at 7:35 p.m. According to the neonatologist, the baby was breathing irregularly

on her own at birth. After a few minutes of observation, her breathing became regular. She was wrapped in a blanket and taken to the nursery. She was kept warm, dry and fed. A hat was put on her head. In accordance with her parents' wishes, no tubes, other than feeding tubes and intravenous lines, were ever inserted into the child. Baby Avery was connected to monitoring equipment. The Ms and the neonatologist agreed that Baby Avery would not be resuscitated when she began to die.

According to the Ms, Baby Avery was "perfect from the eyebrows down." As the ultrasound had revealed, she had no upper portion of her skull and her brain stem was visible through the open scalp. "They told us she would only live two hours," said Mrs. M, but she lived two and one-half days. The Ms spent time, over the two day period, holding and photographing Baby Avery. When Baby Avery's heart rate began to slow, signifying that she was dying, she was brought to the Ms, where she was held until she died. "I don't know that she didn't feel anything," says Mrs. M. As she was dying, "she would cry and her knuckles would tighten." "The doctors told me that she didn't feel anything, but I don't believe that—how do they know what she's feeling and what she's going through." Baby Avery died at 7:35 a.m. on November 13, 1995.

Both Mr. and Mrs. M feel strongly that Baby Avery should have been allowed to donate her organs. Reflecting on that time, both Mr. and Mrs. M remarked on Baby Avery's strong and healthy heart. "Her heart was very strong—a great heart. Her heart would be a great transplant," said Mr. M. "I really wanted this done," remembered Mr. M, but "they backed off because of legal issues." They said they "couldn't harvest organs from patients who are alive . . . [and] couldn't pronounce [the baby] brain dead." Despite being disappointed that Baby Avery could not be an organ donor, the Ms' were very pleased with the care they and their babies received at the hospital.

The issues surrounding organ donation by anencephalic infants such as Baby Avery are complex for all involved. This Article will examine anencephalic organ donation⁴ by providing an overview of the legal, medical, social, and ethical issues that hospital counsel

4. For an excellent overview of the issues surrounding anencephalic organ donation, see Calvin R. Stiller et al., *Organ and Tissue Transplants*, in 5 *ENCYCLOPEDIA OF BIOETHICS* 1871, 1871-94 (Warren Thomas Reich ed., revised ed. 1995). For another legal discussion of anencephalic organ donation, see Jay A. Friedman, Note, *Taking the Camel by the Nose: The Anencephalic as a Source for Pediatric Organ Transplants*, 90 *COLUM. L. REV.* 917 (1990). Although Friedman's article was written prior to legal

and ethics committees will face when presented with anencephalic organ donation scenarios. This discussion will be framed by recounting recent cases involving parents who wanted to donate their anencephalic infant's organs. Furthermore, this Article will propose that the topic of anencephalic organ donation be thoroughly discussed and well understood in every medical/legal setting in which an anencephalic infant may present itself. Preferably, this should happen when there is no case pending so that policies can be drafted without the time pressures of a pending case. It is essential that transplant teams, organ procurement centers, lawyer-ethicists, obstetricians, hospital counsel, maternal-fetal medicine specialists, and neonatologists all share a common understanding of anencephaly. Once an understanding is shared, parents of an anencephalic infant will not be subjected to any greater pain and confusion, due to miscommunication, than that which already surrounds the death of their child.

I. ANENCEPHALY

A. *What Is Anencephaly?*

A diagnosis of anencephaly in an infant, prenatally or at birth, is a tragedy for all concerned. Anencephaly is a birth defect in which "(1) [a] large portion of the skull is absent[;] (2) [t]he scalp, which extends to the margin of the bone is absent over the skull defect[;] (3) [h]emorrhagic, fibrotic tissue is exposed because of defects in the skull and scalp[; or] (4) [r]ecognizable cerebral hemispheres are absent."⁵ Anencephalic infants lack the brain function necessary for maintaining prolonged independent respiration and are prone to severe infections from their open heads.⁶ Further, infants with anencephaly are believed to be permanently unconscious. As one blunt commentator has noted, "[normal brain] stems do not differ substantially from the brain stem of a fish, [and an anencephalic infant] has more in common with a fish than a person."⁷ While there are anecdotal reports of survival by anencephalic infants for a few days, weeks, or even years, most

decisions which have affected the law regarding anencephalic infants, it raises and analyzes several issues that remain important today.

5. Task Force, *supra* note 2, at 670.

6. *See id.* at 669.

7. Sabra Chartrand, *Legal Definition of Death Is Questioned in Florida Infant Case*, N.Y. TIMES, Mar. 29, 1992, § 1, at 12. While this quotation has made its way into the popular lexicon of anencephalic organ donation, its source, Dr. Robert Levine, explains that he did not intend to compare the baby with a fish. Rather, he was making an

anencephalic infants die at, or soon after, birth.⁸

B. *Anencephaly in the Context of Organ Donation*

For parents, a diagnosis of anencephaly foretells the ultimate death of their child. For a medical staff, a diagnosis of anencephaly means presiding over an infant's death rather than the beginning of a new life. For hospital counsel, a diagnosis of anencephaly triggers a number of legal and ethical issues that must be resolved quickly and often under great stress. Parents will sometimes, in light of publicity about the need for pediatric organ donors, bring up the issue of organ donation soon after hearing the diagnosis. This request will usually trigger an emergency meeting of the hospital's ethics committee, which will then have to make a recommendation in the face of little or no information.⁹

In order to be considered for organ donation, an anencephalic infant must be deemed brain dead.¹⁰ In the context of anencephaly, unfortunately, the brain death standard is often misunderstood by counsel advising the ethics committees, by the medical community, in general, and by parents who are told on the one hand that their baby lacks a brain, but on the other hand that their baby cannot be an organ donor due to residual brain function. Counsel must therefore have a solid understanding of the legal standards of death in order to adequately advise clients in this area.

A human being must be legally brain dead before becoming an

observation on brain function. Interview with Robert Levine, M.D., Professor, Yale University, in New Haven, Conn. (Mar. 31, 1999).

8. See E. Haavi Morreim, *Futilitarianism, Exoticare and Coerced Altruism: The ADA Meets Its Limits*, 25 SETON HALL L. REV. 883, 886 (1995) ("Quantitatively, [treatment] is futile because an anencephalic [infant] will die soon no matter what physicians do.").

9. See generally Robert M. Nelson & Robyn S. Shapiro, *The Role of an Ethics Committee in Resolving Conflict in the Neonatal Intensive Care Unit*, 23 J. L. MED. & ETHICS 27 (1995).

10. Most states use the Uniform Determination of Death Act ("UDDA") to determine whether a person is alive or dead. The UDDA provides the following:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards.

UNIF. DETERMINATION OF DEATH ACT § 1, 12A U.L.A. 593 (1996).

In Washington, D.C., doctors are authorized to extract and preserve organs for transplant even before receiving the family's consent. However, such consent must be obtained before actual transplantation may occur. See D.C. CODE ANN. § 2.1509.1 (Supp. 1998); see also Rick Weiss, *Demand for Organs Fosters Aggressive Collection Methods*, WASH. POST, Nov. 24, 1997, at A1.

organ donor, except where an organ, such as a kidney, can be donated without ending the life of the donor.¹¹ Since an anencephalic infant retains basic brain functions, it cannot meet this current standard of brain death.¹² Therefore, in almost every case, anencephalic organ donation cannot be accomplished.¹³ The only exception is for tissue donation, such as corneas and heart valves, which can be harvested after clinical death.¹⁴ The solid organs are buried with the infant, in essence adding to the shortage of pediatric donors and placing tremendous pressure on both families of potential organ recipients and the medical personnel treating those patients.¹⁵ Despite the small percentage of the potential donor pool that they comprise, anencephalic infants draw a fair amount of attention as potential organ donors.

The issue of anencephalic organ donation is hotly debated and has generated significant comment from doctors, lawyers, and ethicists.¹⁶ A leading article in the *Journal of the American Medical Association* in 1989, authored in part by Alexander Capron and Alan Shewmon, provided the seminal analysis of public health, legal, medical, and ethical issues raised by anencephalic organ donation.¹⁷ The article predicted that anencephalic infants would never be a significant source of donor organs due to ethical and legal difficulties.¹⁸ Ten years later, many of the article's predictions about attempts to use anencephalic infants as organ donors have proven accurate. Most notably, major advances in prenatal diagnosis have dramatically reduced the number of potential anencephalic organ donors, thereby strengthening the contention that the actual number of such organs available is so small that anencephalic infants cannot provide a realistic answer to the critical shortage of

11. For a discussion of the determination of whether a person is alive or dead, see *supra* note 10.

12. See Norman Fost, *Removing Organs from Anencephalic Infants: Ethical and Legal Considerations*, 16 *CLINICS IN PERINATOLOGY* 331, 333 (1989).

13. See Task Force, *supra* note 2, at 671.

14. See Rene Lafreniere & Mary H. McGrath, *End of Life Issues: Anencephalic Infants as Organ Donors*, 1998 *J. AM. C. SURGEONS* 443, 445.

15. See generally Kathleen L. Paliokas, *Anencephalic Newborns as Organ Donors: An Assessment of "Death" and Legislative Policy*, 31 *WM. & MARY L. REV.* 197 (1989).

16. See, e.g., D. Alan Shewmon et al., *The Use of Anencephalic Infants as Organ Sources*, 261 *JAMA* 1773 (1989); George J. Annas, *From Canada with Love: Anencephalic Newborns as Organ Donors*, *HASTINGS CENTER REP.*, Dec. 1987, at 36.

17. See Shewmon et al., *supra* note 16.

18. See *id.* at 1780.

infant donor organs.¹⁹ Nonetheless, the issues raised by anencephalic organ donation remain important in light of present day attempts to increase the pool of potential organ donors by including those without a functioning consciousness, such as people in permanent vegetative states.

II. THE ORGAN DONATION SYSTEM

Organ donation in the United States is highly regulated by state and federal laws. The federal government regulates organ donation through the National Organ Transplant Act ("NOTA").²⁰ In addition, every state has enacted the Uniform Anatomical Gift Act ("UAGA"),²¹ which grants individuals and, after death, their family members the right to decide whether or not to donate organs.²² Under both the federal and state laws, it is a crime for any person to pay money for an organ.²³ Thus, a person in need of an organ transplant must rely on a volunteer donor rather than personal acquisition of an organ; unfortunately, the system of matching recipients with volunteer donors is very complex.²⁴

19. The number of anencephalic babies born has dropped steadily since the 1960's. *See id.* at 1774. The sharp decline in the number of reported births of anencephalic infants, along with the growing, almost universal practice of screening every pregnancy with ultrasound, has made it interesting to revisit Capron and Shewmon's analysis of how many organs would actually be available for donation by anencephalic infants. *See id.* at 1774-75.

Assuming 4 million live births a year, rather than the 3.5 million used by Shewmon and Capron in 1989, and 0.3 cases of anencephaly per 1000 births, there should be 1200 potential organ donors born in the United States every year. *See id.* at 1774. Approximately 20% of pregnancies are screened for neural tube defects during the second trimester, *see id.*, resulting in 240 cases detected. Approximately 95% of these pregnancies are likely to be terminated, *see id.*, making the number of anencephalic births around 970 per year. Shewmon and Capron estimate that 66% of anencephalic infants are still born, *see id.*, reducing the total live births to 330. Of these, Shewmon and Capron estimate that 60% are too small to serve as organ donors, leaving 132 infants. If, again as Shewmon and Capron estimate, two thirds of the parents are willing to use their infants as donors, *see id.*, there would be 87 donors. These 87 potential donors are not sufficient to meet the need for pediatric organs.

This update of Shewmon and Capron's analysis only strengthens their point that the available pool of anencephalic infants is too small to be a significant factor in increasing organ availability. *See id.* at 1774-75, 1780.

20. *See* 42 U.S.C. §§ 273-274e (1994).

21. *See* UNIF. ANATOMICAL GIFT ACT, 8A U.L.A. 19 (1993).

22. *See* UNIF. ANATOMICAL GIFT ACT § 3, 8A U.L.A. 40 (1993).

23. *See* 42 U.S.C. § 274e; UNIF. ANATOMICAL GIFT ACT § 15, 8A U.L.A. 62 (1993).

24. Organ transplantations are administered in hospitals by organ procurement teams which operate under United Network for Organ Sharing ("UNOS") guidelines to harvest organs and make them available to patients in need. The organ procurement

Perhaps the greatest issue currently facing pediatric transplantation is that of organ supply. For some children, especially infants with heart conditions, a transplant is their only chance for long term survival.²⁵ In fact, the single most needed organs for children are hearts and, to some extent, livers.²⁶ Moreover, the scarcity of pediatric organs creates intense demand. Thus, the issue of pediatric organ donation has become a major public health concern.²⁷ Numerous plans and proposals to increase the availability of pediatric organ donors have been brought forward, including proposals to increase the supply of organs from humans,²⁸ animals,²⁹ and anencephalic infants.³⁰

team may already be involved by the time the issue of organ donation reaches counsel, as was the case with Baby Avery. Counsel should not rely on the organ procurement team to manage the issue. The question of anencephalic organ donation may never have occurred at the particular medical center. Even in centers with policies governing anencephalic organ donation, the organ procurement team can, as was the case with Baby Avery, unreasonably raise expectations by failing to adequately explain the issue of brain death.

25. These infants are particularly good candidates for transplant since they are usually healthy in every way except for their heart defect. Moreover, since infants are much less likely to reject a heart than adults, transplantation is a "rational, durable therapy" for hypoplastic left heart syndrome. Howard P. Gursesell & Thomas A. Masaro, *Management of Hypoplastic Left Heart Syndrome in a Consortium of University Hospitals*, 76 AM. J. CARDIOLOGY 809, 810 (1995); see also Leonard L. Bailey et al., *Bless the Babies: One Hundred Fifteen Late Survivors of Heart Transplantation During the First Year of Life*, 105 J. THORACIC & CARDIOVASCULAR SURGERY 805 (1993).

26. See Ingrid Kinkopf-Zajac, *Assessing Patient Compliance in the Selection of Organ Transplant Recipients*, 6 HEALTH MATRIX 503, 521-23 (1996) (explaining that livers and hearts are especially needed for transplants because patients in need of these organs will die if denied an organ, unlike an organ such as a kidney for which there are alternative methods to sustain life other than an organ transplant).

27. While there is no formal cost-benefit analysis of infant organ transplantation, one leading commentator recently noted that "the cost of many other forms of medical care is on a par with transplantation." Arthur L. Caplan, *Current Ethical Issues in Organ Procurement and Transplantation*, 272 JAMA 1708, 1708-09 (1994).

28. One of the most extreme proposals for increasing the availability of organs is an "organ draft [which] would empower the state to conscript every cadaveric organ suitable for transplantation without regard to any contrary wishes expressed by the decedent while he lived or by surviving relatives after he dies." Theodore Silver, *The Case for a Post-Mortem Organ Draft and a Proposed Model Organ Draft Act*, 68 B.U. L. REV. 681, 681 (1988). Another suggestion is to pay families to release their relative's organs for donations. See *Developments in the Law—Medical Technology and the Law*, 103 HARV. L. REV. 1519, 1623-29 (1990).

29. See generally Charles R. McCarthy, *Bioethics Inside the Beltway: A New Look at Animal-to-Human Organ Transplantation*, 6 KENNEDY INST. ETHICS J. 183 (1996).

30. See, e.g., Beth Brandon, Note, *Anencephalic Infants as Organ Donors: A Question of Life or Death*, 40 CASE W. RES. L. REV. 781 (1989-90); Friedman, *supra* note 4; Andrea K. Scott, Note, *Death Unto Life: Anencephalic Infants as Organ Donors*, 74 VA. L. REV. 1527 (1988).

III. ORGAN DONATION BY ANENCEPHALIC INFANTS

A. *A Court's Analysis: The Baby Theresa Case*

The issues surrounding the use of anencephalic infants as organ donors was the topic of much debate, but very little legal guidance, until the case of Theresa Ann Campo Pearson ("Baby Theresa") arose in Florida.³¹ In 1992, with the birth of Baby Theresa, the legality of anencephalic organ donation was tested for the first time in United States' courts.³² Baby Theresa was diagnosed prenatally with anencephaly and her mother agreed to a caesarean section "with the express hope that the infant's organs would be less damaged and could be used for transplant in other sick children."³³ Baby Theresa's birth sparked an intense debate in the legal community regarding the legal restrictions on organ donation.³⁴

A fundamental legal principle of organ donation requires the donor, or his family, to consent to the donation.³⁵ While no specific law requires that organ donation be undertaken voluntarily, the forcible invasion of a person's bodily integrity to obtain an organ is a crime just like any other assault.³⁶ When the prospective donor is a minor, the process is even more highly regulated, with great care taken to avoid exploitation.³⁷ The events of Baby Theresa's life are well known. The child's parents were told in the eighth month of pregnancy that their daughter was anencephalic and would either be born dead or live for just a few minutes.³⁸ The doctors suggested

31. See *In re T.A.C.P.*, 609 So. 2d 588 (Fla. 1992). See generally J. Steven Justice, Casenote, *Personhood and Death—the Proper Treatment of Anencephalic Organ Donors Under the Law: In Re T.A.C.P.*, 609 So. 2d 588 (Fla. 1992), 62 U. CIN. L. REV. 1227 (1994).

32. See Joseph M. Healey, *Ends and Means in Organ Transplantation: The Anencephalic Donor*, 57 CONN. MED. 49, 49-50 (1993).

33. *T.A.C.P.*, 609 So. 2d at 589.

34. See, e.g., Daniel Avila, *Medical Treatment Rights of Older Persons and Persons with Disabilities: 1992-93 Developments and Emerging Trends*, 9 ISSUES L. & MED. 345 (1994); Lisa E. Hanger, *The Legal, Ethical and Medical Objections to Procuring Organs from Anencephalic Infants*, 5 HEALTH MATRIX 347 (1995); Justice, *supra* note 31; David T. McDowell, Note, *Death of an Idea: The Anencephalic as an Organ Donor*, 72 TEX. L. REV. 893 (1994).

35. See UNIF. ANATOMICAL GIFT ACT § 3, 8A U.L.A. 40 (1993).

36. See *Strachan v. John F. Kennedy Mem'l Hosp.*, 638 A.2d 346 (N.J. 1988); see also Kevin P. Quinn, Comment, *The Best Interests of Incompetent Patients: The Capacity for Interpersonal Relationships as a Standard for Decisionmaking*, 76 CAL. L. REV. 897 (1988) (describing the common law right to freedom from nonconsensual invasions of bodily integrity and the federal constitutional right to privacy).

37. See ANGELA RODDEY HOLDER, *LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE* 167-72 (2d ed. 1985).

38. See *T.A.C.P.*, 609 So. 2d at 589.

a third-trimester abortion, but also explained that the baby would be a candidate for organ donation if she were carried to term.³⁹

Theresa's parents decided not to pursue an abortion but instead to donate her organs.⁴⁰ For a short period after birth, the baby was placed on a mechanical ventilator as a precautionary measure.⁴¹ However, Baby Theresa continued to breathe after she was removed from life support; thus, she became ineligible to be declared dead under an applicable Florida statute.⁴² Faced with this change in circumstances, the hospital refused to consider the child as an organ donor "out of concern that [it] might incur civil or criminal liability."⁴³ The hospital's action triggered a legal petition by the parents which sought to declare Theresa dead so that her organs could be donated.⁴⁴

The trial court held that, under Florida law, Baby Theresa was ineligible to be declared dead since she was surviving without life support and her brain stem continued to function.⁴⁵ Theresa's parents appealed; the Florida District Court of Appeal for the Fourth District "summarily affirmed but then certified the trial court's order to [the Florida Supreme Court] for immediate resolution of the issue."⁴⁶ Although Baby Theresa died during the pendency of the appeal,⁴⁷ the Florida Supreme Court agreed to decide the case in order to establish a legal precedent.⁴⁸ In *In re T.A.C.P.*,⁴⁹ the court recognized Theresa's parents' intent in pursuing the action by stating "[w]e have been deeply touched by the altruism and unquestioned motives of the parents of [Baby Theresa]. The parents have shown great humanity, compassion, and concern for others."⁵⁰ The court also recognized the pressing need for organ donors, writing

39. See *id.*; see also Frank A. Chervenak et al., *When Is Termination of Pregnancy During the Third Trimester Morally Justifiable?*, 310 NEW ENG. J. MED. 501, 501-03 (1984) (explaining the process of third trimester abortions).

40. See *T.A.C.P.*, 609 So. 2d at 589. The baby was delivered by cesarean section on March 21, 1991, to reduce trauma to the organs. See *id.*

41. See *id.*

42. The court stated that "the evidence shows that [Baby Theresa's] heart was beating and she was breathing at the times in question. Accordingly, she was not dead under Florida law, and no donation of her organs would have been legal." *Id.* at 595.

43. *Id.* at 589.

44. See *id.*

45. See *id.*

46. *Id.*

47. See *id.* at 589 n.2.

48. See *id.* at 589.

49. 609 So. 2d 588 (Fla. 1992).

50. *Id.* at 594.

"[t]here . . . is no doubt that a need exists for infant organs for transplantation. Nationally, between thirty and fifty percent of children under two years of age who need transplants die while waiting for organs to become available."⁵¹

The court then analyzed common law and statutory law and found that, under common law, a person is viewed as being dead when he can no longer breathe and his blood stops circulating.⁵² Considering rapid advances in medical technology, most states have adopted the Uniform Determination of Death Act.⁵³ Florida, however, as recognized by the court, enacted a statute that requires "irreversible cessation of the functioning of the entire brain, including the brain stem" before a person may be viewed as dead.⁵⁴

The Florida Supreme Court, in *T.A.C.P.*, concluded that the Florida statute applied to persons on life support only.⁵⁵ At the time her parents brought the petition, Baby Theresa was breathing on her own without the need for life support. Thus, the court concluded that "[t]he evidence shows that [Baby Theresa's] heart was beating and she was breathing at the times in question. Accordingly, she was not dead under Florida law, and no donation of her organs would have been legal."⁵⁶ Importantly, the court decided not to read an exception for anencephalic infants into the law, noting that "the 1988 Florida Legislature considered a bill that would have defined 'death' to include anencephaly" but rejected it.⁵⁷

51. *Id.* at 591 (citing Joyce L. Peabody et al., *Experience with Anencephalic Infants as Prospective Organ Donors*, 321 NEW ENG. J. MED. 344, 344 (1989)).

52. *See id.* at 591-93.

53. UNIF. DETERMINATION OF DEATH ACT, 12A U.L.A. 589 (1996). The *T.A.C.P.* court recognized the existence of the Uniform Act and quoted its language: "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. A determination of death must be made in accordance with accepted medical standards." *T.A.C.P.*, 609 So. 2d at 592 (quoting UNIF. DETERMINATION OF DEATH ACT § 1, 12 U.L.A. 340 (Supp. 1991)).

54. *T.A.C.P.*, 609 So. 2d at 592. The entire statutory section reads as follows: For legal and medical purposes, where respiratory and circulatory functions are maintained by artificial means of support so as to preclude a determination that these functions have ceased, the occurrence of death may be determined where there is the irreversible cessation of the functioning of the entire brain, including the brain stem, determined in accordance with this section.

FLA. STAT. ANN. § 382.009(1) (West 1998). A later subsection explains further that "[e]xcept for a diagnosis of brain death, the standard set forth in this section is not the exclusive standard for determining death or for the withdrawal of life support systems." *Id.* § 382.009(4).

55. *See T.A.C.P.*, 609 So. 2d at 592.

56. *Id.* at 595.

57. *Id.* at 593. The court noted the following: "The bill died in committee. While

B. *The Rise of Organ Donation by Anencephalic Infants*

Some critics of anencephalic organ donation might question the technical feasibility of such transplants. As medical technology has advanced, however, it has become increasingly possible to support organs by keeping anencephalic infants oxygenated through mechanical life support.⁵⁸ Furthermore, medical literature indicates that transplanting organs from anencephalic infants is possible.⁵⁹ This technical feasibility, combined with the possibility of preserving the anencephalic infant's visceral organ functions when born, and the inevitability of the anencephalic infant's death, has led physicians to view these infants as potential organ donors.⁶⁰ Viewing anencephalic infants as potential organ donors has brought on great debate and angry protest from many organizations.⁶¹

The issue of anencephalic organ donation reached widespread public attention for the first time in 1968, when one of the first successful heart transplants was performed using an anencephalic infant as a donor.⁶² After this success, programs for harvesting organs from anencephalic infants became widespread, especially outside of the United States. There were reports during the late

the failure of legislation in committees does not establish legislative intent, it nevertheless supports the conclusion that as recently as 1988 no consensus existed among Florida's lawmakers regarding the issue we confront today." *Id.*

58. Since the mother's "life support system" supports the fetus' growth in the womb, anencephalic infants who survive to term frequently, but do not always, do so with all of their internal organs intact and well formed. What goes wrong, in basic terms, is that there is no brain or nervous system to take over at birth. In every case of true anencephaly, the baby lacks the parts of the brain that regulate "consciousness, thought, memory and feeling." Scott, *supra* note 30, at 1527 n.4.

59. See Task Force, *supra* note 2, at 672. There are some restrictions, however, on the use of an anencephalic's organs for transplantation. First, anencephalic infants are often premature and weigh less than 2,000 grams. See *id.* This can result in organs too small to be of use. See *id.* Also, in some cases anencephaly is associated with other birth defects which affect the organs. See *id.*

60. In fact, there have been reported cases of anencephalic organ transplantation in the United States. George Annas reports that the first human to human transplant in the United States was done in 1968 by Adrian Kantrowitz, and actually involved an anencephalic infant as a donor. See Annas, *supra* note 16, at 37.

61. The following organizations filed amicus briefs opposing the use of Baby Theresa's organs in the *T.A.C.P.* case: Americans United for Life and Florida Right to Life; the American Civil Liberties Union Foundation of Florida, Inc.; the Arc, Ethics and Advocacy Task Force of the Nursing Home Action Group; the United Network for Organ Sharing; and the Advocacy Center for Persons with Disabilities, Inc. See *T.A.C.P.*, 609 So. 2d at 588. See Shewmon et al., *supra* note 16, for a further discussion of this opposition.

62. See *supra* note 60 for a brief discussion of this transplant.

1980's of kidney transplants from West Germany⁶³ and Spain.⁶⁴

C. *The Medical Community's Response to Using Anencephalic Infants as Organ Donors*

In December of 1994, the Council on Ethical and Judicial Affairs ("CEJA") reversed their long standing position that an anencephalic infant must be declared dead in order to be treated as an organ donor.⁶⁵ CEJA is a subdivision of the American Medical Association ("AMA"), which interprets the principles of medical ethics for the AMA.⁶⁶ Rather than require an anencephalic infant to be declared dead before organ donation, as the AMA had done in the past, CEJA's 1994 opinion provided that organs could be obtained from a still living anencephalic infant.⁶⁷ CEJA supported this position by reasoning that anencephalics have no consciousness and therefore do not have the rights of human beings.⁶⁸ The AMA adopted the opinion and it was, for a short time, the official position of the AMA that organs could be harvested from a living anencephalic infant.⁶⁹ A public and professional outcry followed this announcement.⁷⁰ Physicians, parents of handicapped infants, and clergymen were all opposed to the new position.⁷¹ Reacting to the protest, the AMA took the unusual action of having a public hearing on the issue.⁷² Based on the results of that hearing, CEJA suspended its position, thus returning to the position that the AMA had held since 1982: an anencephalic infant must be declared dead in order to be treated as an organ donor.⁷³

The AMA's retreat reflected the feelings of a substantial number of physicians who were not comfortable with using anencephalic neonates as organ donors. This decision was based on

63. See generally Wolfgang Holzgreve et al., *Kidney Transplantation from Anencephalic Donors*, 316 NEW ENG. J. MED. 1069 (1987).

64. See generally F.J. Gomez-Campdera et al., *Kidney Transplantation from Anencephalic Donors*, 10 CHILD NEPHROLOGY & UROLOGY 143 (1990).

65. See James Walters et al., *Anencephaly: Where Do We Now Stand?*, 17 SEMINARS IN NEUROLOGY 249, 250-57 (1997).

66. See *id.* at 249-50.

67. See *id.* at 250-51.

68. See *id.* at 251 (quoting Council on Ethical and Judicial Affairs, *The Use of Anencephalic Neonates as Organ Donors*, 273 JAMA 1614, 1615 (1995) [hereinafter CEJA]).

69. See *id.*

70. See *id.*

71. See *id.*

72. See *id.*

73. See *id.*

“reports from the scientific community that question[ed] the assumption that all infants with anencephaly lack consciousness.”⁷⁴ It is therefore arguable that the AMA implicitly retained the position that an anencephalic infant that lacks consciousness can be considered as an organ donor, even if the infant does not meet the legal standards of death.⁷⁵

IV. SOCIAL CONSIDERATIONS IMPACTING ORGAN DONATION BY ANENCEPHALIC INFANTS

There are a number of social concerns surrounding anencephalic organ donation. Many groups, such as pediatricians, parents of anencephalic infants, parents of children in need of organs, and political issue groups that oppose any taking of human life, frequently express their opinions on this issue. In fact, the AMA's decision to suspend its policy on anencephalic organ donation was spurred by protest from the medical community.⁷⁶ The protest included activities by anti-abortion groups, such as the National Right to Life Committee (“NRLC”), which views anencephalic infants as alive because they are born with a brain stem.⁷⁷ Since, the NRLC is committed to preserving life in all of its forms, including that of the fetus, it opposes using the anencephalic infant as an organ donor.⁷⁸

Another group that opposes declaring anencephalic infants dead for the purpose of organ donation is the Advocacy Center for Persons with Disabilities, Inc. (“ACPD”), which protects and advo-

74. Diane M. Gianelli, *Ethics Council Reverses Stand on Anencephalic Organ Donors*, AM. MED. NEWS, Dec. 25, 1995, at 3.

75. See generally Walters et al., *supra* note 65, at 250-57. With the withdrawal of the December 1994 position, the AMA's position on anencephalic infants as organ donors is that:

Physicians may provide anencephalic infants with ventilator assistance and other medical therapies that are necessary to sustain organ perfusion and viability until such time as a determination of death can be made in accordance with accepted medical standards and relevant law. Retrieval and transplantation of the organs of anencephalic infants are ethically permissible only after such determination of death is made, and only in accordance with the Council's guidelines for the transplantation.

Charles W. Plows, *The Use of Anencephalic Neonates as Organ Donors—Reconsideration*, in COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, PROCEEDINGS OF THE HOUSE OF DELEGATES OF THE AMERICAN MEDICAL ASSOCIATION, 49TH INTERIM MEETING 225, 225 (1995).

76. See *supra* Part III.C for a discussion of the AMA's response to such protest.

77. See Walters et al., *supra* note 65, at 251; see also Scott, *supra* note 30, at 1555-58 (explaining the views of NRLC in general).

78. See Scott, *supra* note 30, at 1555.

cates for persons with disabilities. The ACPD is concerned about the fate of anencephalic infants because of its mission to advocate for those members of society who must struggle daily against those who would classify them unfairly.⁷⁹ Relaxing the "whole brain death" criteria for anencephaly may lead to relaxing the criteria for other persons with disabilities, for example, those with hydrencephaly or microencephaly.⁸⁰ Finally, there is substantial opposition to anencephalic organ donation by neurologists and pediatricians who argue that any person with a brain stem is alive and therefore cannot be a source of donor organs.⁸¹

V. LEGAL ISSUES SURROUNDING ORGAN DONATION BY ANENCEPHALIC INFANTS

A. *The Parental Right to Withhold Treatment*

Hospital counsel and ethics committees must consider whether parents have a right to withhold treatment from their anencephalic infant. Generally speaking, parents have a right to withhold treatment from their children.⁸² In fact, parents have a constitutional right to make several decisions for their children.⁸³ However, when the patient is a newborn infant, statutes often limit the choices

79. See *supra* note 61 (explaining that the ACPD filed an amicus brief in the *T.A.C.P.* case). See generally *Krischer v. McIver*, 697 So. 2d 97, 101-02 (briefly explaining the views of the ACPD).

80. One advocate for the disabled has written the following:

Children born with disabilities deserve the same respect and honor as able-bodied infants. Somehow, in the quest for medical breakthroughs, we have forgotten what is decent and fair. The issue is not what will make parents feel better or meet the needs of others but what is right for this child! It doesn't matter if a baby has 6 seconds or 60 years to live. What does matter is that any child born with a disability has value and deserves to be recognized as such.

Brenda Bondurant, *Babies and Organs*, VIRGINIA-PILOT, July 27, 1995, at A12. See *supra* notes 10-11 and accompanying text for a discussion of the "whole brain death" standard.

81. As one neurologist interested in the issue of anencephalic organ donation explains, neurologists are "the keepers of the holy grail" in deciding who is alive and who is not. "Our job," she explains, is "to keep things clear," not to be swayed by the good it might do for others if a baby is declared dead. Referring to the slippery slope, the doctor explained that as far as brain function is concerned, anencephalic infants are in exactly the same situation as people in permanent vegetative states: both lack all but brain stem function. Nevertheless, there is no movement to declare persons in a permanent vegetative state dead for any reason, including the taking of organs. Interview with Carol Leicher, M.D., Associate Professor of Pediatrics and Neurology, University of Connecticut School of Medicine, in Hartford, Conn. (June 30, 1996).

82. See *In re L.H.R.*, 321 S.E.2d 716, 722 (Ga. 1984) (allowing the withholding of treatment from a patient in a chronic vegetative state).

83. See generally *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (allowing Amish par-

available to parents. For example, the Child Abuse Prevention and Treatment and Adoption Reform statutes, commonly referred to as the Baby Doe statutes, provide that doctors and parents are prohibited from subjecting an infant to medical neglect.⁸⁴ The Baby Doe statutes provide that treatment can be withheld from an infant with a life threatening condition only under a set of very specific circumstances. Treatment need not be offered when:

- (A) the infant is chronically and irreversibly comatose;
- (B) the provision of such treatment would (i) merely prolong dying, (ii) not be effective in ameliorating or correcting all of the infant's life threatening conditions, or (iii) otherwise be *futile* in terms of the survival of the infant; or
- (C) the provision of such treatment would be virtually *futile* in terms of the survival of the infant and the treatment itself under such circumstances would be *inhumane*.⁸⁵

Application of the Baby Doe statutes to anencephalic infants is quite complicated. The term "futile" is legally and medically ambiguous. What, for example, is the time frame of the futility? Minutes, days, or years? Looking at another aspect of the statute, counsel may wonder what would constitute inhumane treatment of an infant if it cannot suffer.⁸⁶ Are we sure that anencephalic infants do not suffer? The question remains, do the parents of an

ents to ignore a compulsory school attendance law due to its conflict with the parents' fundamental right to guide their children's religious beliefs).

84. See generally 42 U.S.C. §§ 5101-5107, 5111-5119c (1994 & Supp. II 1996).

85. *Id.* § 5106g (emphasis added).

86. The philosopher Hans Jonas disagrees with an interpretation of the Baby Doe statutes which concludes that an infant who cannot feel does not have to be treated humanely. There is an obligation we all have to treat living creatures with respect, regardless of their ability to process or understand pain. See *infra* Part VI.E for a discussion of the views of Hans Jonas.

Until quite recently, no infant was given anesthesia before surgery because current medical wisdom held that their brains, though intact, were not developed sufficiently to experience pain. This has been roundly disproved. The case of anencephalic infants not feeling pain seems stronger since these infants lack the higher brain function currently believed to be necessary to perceive pain. The issue of pain and suffering coats the surface of the larger issue of whether these anencephalic infants are human, and therefore entitled to basic human rights. Would it, for example, be appropriate to use an anencephalic infant for vivisection? The AMA seems to be dangerously close to asking this question in their effort to determine definitively if anencephalic infants feel. It is this author's opinion that whether these infants feel or not, they are human and entitled to full human rights. Viewed in this light, an anencephalic infant has the same rights as any human to forego medical treatment when that treatment would not result in a clear, long-term benefit.

anencephalic infant have the right to refuse treatment? The answer would appear to be yes.

Parents arguably have a right to refuse treatment for their anencephalic infant as analogous case law already supports this proposition.⁸⁷ There has been, however, no legal case questioning a parent's decision to withhold or withdraw life saving technology from an anencephalic infant. Given the strong consensus in the medical community that anencephaly is a condition incompatible with life,⁸⁸ it is unlikely that an interloper could, through the legal system, force parents to treat an anencephalic infant.

The Baby Doe statutes state explicitly that treatment is not required when the infant is permanently unconscious. This overriding principle cuts through the haze of futility and suffering to arrive at the core issue that these infants lack the brain tissue necessary for consciousness. Still, hospitals must determine whether they themselves have an obligation to treat an anencephalic infant.

B. *The Hospital's Obligation to Treat: Baby K's Case*

In 1992, a child, known to the courts as Baby K, was diagnosed prenatally with anencephaly.⁸⁹ Baby K's mother did not want to abort; rather, she wanted to continue with the pregnancy.⁹⁰ As soon as she was born, Baby K began having difficulty breathing and was placed on life support equipment.⁹¹ The physicians made a definitive diagnosis of anencephaly and recommended that the support be removed and a "Do Not Resuscitate" ("DNR") order be entered.⁹² Baby K's mother refused.⁹³ This refusal set in motion a series of events that culminated in two well-publicized court decisions, one in the United States District Court for the Eastern District of Virginia⁹⁴ and one in the United States Court of Appeals for

87. This prediction is based on the case law allowing parents to refuse conventional treatment for their child so long as the conventional treatment has a very low probability of success. See, e.g., *In re Hofbauer*, 398 N.E.2d 1009 (N.Y. 1979) (allowing parents to treat cancer in their child with nutritional or metabolic therapy based on the recommendation of a licensed physician that it was a valid therapy despite contrary arguments that it was not the most often used therapy).

88. See Task Force, *supra* note 2, at 671.

89. See *In re Baby K*, 832 F. Supp. 1022, 1025 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

90. See *id.*

91. See *id.*

92. See *id.*

93. See *id.*

94. *In re Baby K*, 832 F. Supp. 1022 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

the Fourth Circuit.⁹⁵

The treating physicians eventually took the matter to the hospital's ethics committee, which decided that a DNR order was appropriate.⁹⁶ The baby's mother, however, known to the court as Ms. H, disagreed with the ethics committee and arranged to have Baby K transferred to a nursing home with the understanding that if she were again in respiratory distress, the hospital would readmit her.⁹⁷ Over the next two and one-half years, Baby K returned to the hospital several times for resuscitation and respiratory support.⁹⁸ The hospital and its medical staff were being asked to do far more than "allow" the baby to live; they were being asked to do all that was medically possible to keep her alive. Finally, the hospital, joined by the baby's father and a court appointed guardian for Baby K, sought a declaratory judgment to cease ventilator treatment in the case of future respiratory distress.⁹⁹

The district court refused to issue a declaratory order and found instead that removal of life support would violate specific provisions of three different Acts: the Emergency Treatment and Active Labor Act ("EMTALA"), the Rehabilitation Act of 1973, and the Americans with Disabilities Act ("ADA").¹⁰⁰ The Fourth Circuit, considering only EMTALA, upheld the district court's ruling that the hospital's withdrawal of life support would violate the statute.¹⁰¹ The court noted that EMTALA requires a hospital to either stabilize or transfer any patient.¹⁰² The court stated that "the hospital must provide that treatment necessary to prevent the material deterioration of [each patient's medical] condition," regardless

95. *In re Baby "K"*, 16 F.3d 590 (4th Cir. 1994).

96. *See Baby K*, 832 F. Supp. at 1025.

97. *See id.*

98. *See id.* at 1025-26. One interesting discussion of the *Baby K* case considers the ethical issues her care raised with the nursing staff. Many of the nurses caring for her felt that she had no viable quality of life and that it was therefore immoral to keep her alive. For example, "[i]n an average week, this child would be suctioned over 200 times, receive trach care 21 times, have blood drawn at least 2 times, and be manipulated in some other way to receive care 300 times or more." Cindy Hylton Rushton, *The Baby K Case: Ethical Challenges of Preserving Professional Integrity*, 21 PEDIATRIC NURSING 367, 368 (1995).

99. *See Baby K*, 832 F. Supp. at 1026.

100. *See id.* at 1026-29; *see also* Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd (1994); Rehabilitation Act of 1973, 29 U.S.C. §§ 701-797b (1994 & Supp. II 1996); Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (1994 & Supp. II 1996).

101. *See In re Baby "K"*, 16 F.3d 590, 598 (4th Cir. 1994).

102. *See id.* at 594.

of the long term prognosis of the patient.¹⁰³ The Fourth Circuit did not discuss the other statutes. Ultimately, the United States Supreme Court declined to hear the case, thus making the Fourth Circuit decision final.¹⁰⁴

The *Baby K* case did not directly concern organ donation, but it may be crucial to an understanding of the outer boundaries of parents' rights regarding the treatment of anencephalic infants. Although the decisions did not discuss the issue of organ donation, it is arguable that the issue falls within the courts' decisions. However, a recent analysis of the *Baby K* decisions, as they relate to anencephalic organ donation, concludes that neither the legal decisions, nor the statutes considered by the courts have any bearing on parental decisions to donate the organs of an anencephalic infant.¹⁰⁵ Instead, the case focused on a hospital's duty to treat an anencephalic infant at the parent's insistence. Thus, the case is relevant only to resolving issues regarding the duties of a hospital to administer care at the insistence of an outside party, rather than the issue of ceasing such care for purposes of organ donation. For instance, within the scope of the *Baby K* decisions, there may be an issue as to whether third parties can force a hospital to treat an anencephalic infant despite a decision by the baby's parents not to treat that infant.

The district court, in *Baby K*, undertook a careful and cogent constitutional analysis of the matter. It found that a parent has a due process right under the United States Constitution to raise a child as he or she wishes.¹⁰⁶ This right extends to parental¹⁰⁷ deci-

103. *Id.*

104. However, Judge Sprouse, dissenting from the Fourth Circuit Majority Opinion, wrote the following: "In my view, Congress, even in its weakest moments, would not have attempted to impose federal control in this sensitive, private area." *Id.* at 598 (Sprouse, J., dissenting). Instead, Judge Sprouse stated that EMTALA should be applied on a case by case basis, not as a blanket requirement to treat. *See id.* at 599 (Sprouse, J., dissenting).

105. See Mary Crossley, *Infants with Anencephaly, the ADA, and the Child Abuse Amendments*, 11 ISSUES L. & MED. 379, 403-06 (1996).

106. See *In re Baby K*, 832 F. Supp. 1022, 1030 (E.D. Va. 1993), *aff'd*, 16 F.3d 590 (4th Cir. 1994).

107. It is interesting to note that in the *Baby K* case, the mother and father disagreed about the implementation of a DNR order. Citing Ms. H's religious beliefs in favor of life, the court decided that the mother's decision to continue resuscitations would prevail over the interests of the baby's father. *See id.* It should be noted that the United States Supreme Court expressed a limited bias in favor of choosing life in *Cruzan v. Missouri Department of Health*, 497 U.S. 261, 277-79 (1990) (deciding not to withdraw life support from an adult despite parental wish that it be withdrawn).

sions regarding the medical care of children.¹⁰⁸ The district court noted that "there [will be] a 'presumption that . . . parents act in the best interests of [their] child' because the 'natural bonds of affection lead parents to act in the best interests of their children.'"¹⁰⁹ Therefore, the court appeared to be interested in protecting parental decisions as opposed to simply protecting any decision to continue a child's life. As such, a third party may have difficulty challenging a parental decision to cease treatment.

C. *The Obligation to Donate Organs*

Another issue that arises in the context of organ donation by anencephalic infants is whether there is an *obligation* to donate organs. United States law, for the most part, imposes no obligation on any person to help or rescue another person in the absence of a clearly defined legal duty.¹¹⁰ This lack of an obligation contrasts with the duty to rescue found in European and other civil law countries.¹¹¹ In the United States, a strong man may watch a child drown, and as long as he has played no role in placing that child in danger, he will face no legal consequences, either civil or criminal, by failing to save the child.¹¹²

108. See *Baby K*, 832 F. Supp. at 1030 (citing *Parham v. J.R.*, 442 U.S. 584, 603-04 (1979) (dealing with parents' right to commit child to a mental institution)).

109. *Id.* at 1030 (quoting *Parham*, 442 U.S. at 602).

110. See Jay Silver, *The Duty to Rescue: A Reexamination and Proposal*, 26 WM. & MARY L. REV. 423, 424 (1985). However, a few states have enacted "Duty to Rescue" laws. For example, Vermont has enacted a statute that reads as follows:

(a) A person who knows that another is exposed to grave physical harm shall, to the extent that the same can be rendered without danger or peril to himself or without interference with important duties owed to others, give reasonable assistance to the exposed person unless that assistance or care is being provided by others.

(c) A person who willfully violates subsection (a) of this section shall be fined not more than \$100.00.

VT. STAT. ANN. tit. 12, § 519 (1973); see also MINN. STAT. ANN. § 604.05 (West 1988).

111. The United States Constitution's emphasis on individual rights is what distinguishes the United States from many other nations. In countries using the Civil or Napoleonic law system, individuals are often charged with a duty to help others. For example, both Germany and the former Soviet Union impose a duty on citizens to rescue one another. See Ross A. Albert, *Restitutionary Recovery for Rescuers*, 74 CAL. L. REV. 85, 107, 109-10 (1986).

112. See *Handiboe v. McCarthy*, 151 S.E.2d 905 (Ga. Ct. App. 1966) (finding no liability against a defendant who failed to rescue the plaintiff's four year old boy from a swimming pool); see also *Osterlind v. Hill*, 160 N.E. 301 (Mass. 1928) (holding in favor of a defendant who ignored loud cries for help from a man hanging onto an overturned canoe).

The harsh, individualistic concept embodied in the absence of a duty to rescue in the United States has been addressed by the courts in the context of medical rescue. In *McFall v. Shrimp*,¹¹³ a man was dying of aplastic anemia and his only hope for survival was to receive a bone marrow transplant from his first cousin.¹¹⁴ However, the cousin refused to donate. The dying man appealed to a Pennsylvania court, seeking to force his cousin to donate by arguing that the process, while painful, would do the cousin no harm.¹¹⁵ The court refused his request stating that "[o]ur society, contrary to many others, has as its first principle, the respect for the individual, and that society and government exist to protect the individual from being invaded and hurt by another."¹¹⁶

The protection from forcible donation after death is equally strong, if not so clearly rooted, in the law. The United States Court of Appeals for the Sixth Circuit, in *Brotherton v. Cleveland*,¹¹⁷ recently recognized a wife's right to claim control of her husband's dead body. In *Brotherton*, the wife of a car accident victim was asked at the hospital if she would donate her husband's organs. She declined based on her husband's aversion to such a gift.¹¹⁸ Nonetheless, when the coroner received the body for autopsy, he removed the corneas and donated them to an eye bank.¹¹⁹ The wife brought a civil rights action claiming that her property, the body of her husband, had been taken by the state without due process.¹²⁰ The district court dismissed the case stating that "Ohio does not give a surviving custodian a property interest in the body of a decedent."¹²¹ The Sixth Circuit, however, allowed her claim,¹²² finding that the Ohio Uniform Anatomical Gift Act¹²³ governs whether a relative has an interest in a dead body and "expressly grants a right to [the next of kin] to control the disposal of . . . the body."¹²⁴ The court held that the wife had an interest in control of the body, even though that interest was not necessarily characterized as a property

113. 10 Pa. D. & C.3d 90 (1978).

114. *See id.* at 90.

115. *See id.*

116. *Id.* at 91.

117. 923 F.2d 477 (6th Cir. 1991).

118. *See id.* at 478.

119. *See id.*

120. *See id.* at 478-79.

121. *Id.* at 479.

122. *See id.*

123. OHIO REV. CODE ANN. § 2108.01-99 (Banks-Baldwin 1994).

124. *Brotherton*, 923 F.2d at 482.

right.¹²⁵ Instead, the court held that the interest was a “legitimate claim of entitlement” protected by the due process clause of the Fourteenth Amendment.¹²⁶

A well-reported Chicago case again presented the issue of involuntary donation. *Curran v. Bosze*¹²⁷ involved a twelve year-old boy who was dying of leukemia and in need of a bone marrow transplant.¹²⁸ No one in his immediate family was a compatible donor; however, there were three and one-half year-old twins from a subsequent relationship of the boy’s father who may have been compatible.¹²⁹ The boy’s father petitioned the court to force testing of the twins.¹³⁰ The twins’ mother, with whom the father shared custody, refused.¹³¹ After extensive proceedings, during which psychiatrists, anesthesiologists, bone marrow donors, and parents of children who had donated bone marrow to siblings testified, the court upheld the mother’s refusal.¹³² The court reasoned that although the testing and donation would not be unduly painful to the children, considering their mother’s refusal, neither the testing nor the donation could be deemed to be within the twins’ best interests.¹³³ Therefore, the best interests of the prospective donors were given precedence over the best interest of the dying half-brother.¹³⁴

In another of the few reported cases on this issue, *In re Richardson*,¹³⁵ parents in Louisiana sought to donate a kidney from their retarded seventeen year-old son to their thirty-two year-old

125. *See id.*

126. *Id.*

127. 566 N.E.2d 1319 (Ill. 1990).

128. *See id.* at 1321; *see also* Nancy Gibbs, *The Gift of Life—or Else*, TIME, Sep. 10, 1990, at 70.

129. *See Curran*, 566 N.E.2d at 1321.

130. *See id.* at 1320-21.

131. *See id.* at 1321.

132. *See id.* at 1344-45.

133. *See id.* at 1344. “Only where there is an existing relationship between a healthy child and his or her ill sister or brother may a psychological benefit to the child from donating bone marrow to a sibling realistically be found to exist.” *Id.*

134. The court wrote the following:

No matter how small the hope that a bone marrow transplant will cure [the older boy] the fact remains that without the transplant [the older boy] will almost certainly die. The sympathy felt by this court, the circuit court, and all those who have learned of [the older boy’s] tragic situation cannot, however, obscure the fact that, under the circumstances presented in the case at bar, it neither would be proper under existing law nor in the best interests of the 3 1/2-year-old twins for the twins to participate in the bone marrow harvesting procedure.

Id. at 1345.

135. 284 So. 2d 185 (La. Ct. App. 1973).

daughter who was suffering from "an almost total loss of kidney function."¹³⁶ The Louisiana Court of Appeals noted that although it had heard testimony from the boy, his retardation left him with the mental capacity of "a 3 or 4 year old child."¹³⁷ Applying the "ultimate best interest of a minor" test, the court denied permission for the transplant, holding that since a minor was not allowed to donate property "it is inconceivable to us that [the law] affords less protection to a minor's right to be free in his person from bodily intrusion to the extent of loss of an organ unless such loss be in the best interest of the minor."¹³⁸

As a practical matter, donations between family members usually take place without legal intervention. Although sometimes hospital attorneys seek a declaratory judgment from the court before the procedure takes place, these opinions are often not reported decisions.¹³⁹ When both parents give their consent to an intra-family donation, court intervention is rare.

The extent to which intra-family donation is accepted as routine is highlighted by the Ayala scenario in which parents of a girl, Anissa, dying of chronic myelogenous leukemia conceived another child to serve as a bone marrow donor.¹⁴⁰ Despite protests by

136. *Id.* at 186.

137. *Id.*

138. *Id.* at 187.

139. See Melvin Lewis, *Kidney Donation by a 7-Year-Old Identical Twin Child*, 13 J. AM. ACAD. CHILD PSYCHIATRY 221, 229 (1974) (explaining that hospitals often seek declaratory judgments before acting, but that such orders are seldom reported).

140. See David Grogan et al., *To Save Their Daughter from Leukemia, Abe and Mary Ayala Conceived a Plan—and a Baby*, PEOPLE, Mar. 5, 1990, at 44; Anastasia Toufexis, *Creating a Child to Save Another: A "Miracle Baby" Promises Both Blessings and Controversy*, TIME, Mar. 5, 1990, at 56. Interestingly, the Ayalas were driven to this extreme measure because an anonymous perfect bone marrow match refused, at the last minute, to serve as a donor. See Grogan et al., *supra*. Although, at that time, the anonymous donor was the only identifiable person who could save Anissa's life, there was no legal basis for compelling him to do so. See *supra* notes 110-12 and accompanying text (explaining the lack of duty to rescue laws in the United States).

The Ayala case takes on a new meaning in the context of the current issue of cloning. In a case like the Ayalas', creating a clone of Anissa, their sick daughter, would have assured a compatible bone marrow donor. As future parents seek compatible bone marrow for their dying children, what will prevent them, when technology advances to the cloning of humans, from creating another baby with exactly the same genetic make-up? As societal opinion now stands, no authority can prevent adults from procreating. If the parents are willing to welcome and raise a new child, why would the fact that the new baby is guaranteed to save a sibling's life weigh against the conception?

What if, however, the organ required was a heart rather than bone marrow? Parents would not be allowed to use this new mentally intact child as an organ donor. This brief discussion of cloning in the context of the anencephalic serves to clarify the diffi-

ethicists such as George Annas, who declared in *Time* magazine that "children aren't medicine for other people," there were no legal efforts to stop the Ayalas from conceiving the child or to prevent the new baby from becoming a donor.¹⁴¹ When the baby, Marissa, reached the age of fourteen months, her marrow was extracted and transplanted into Anissa.¹⁴² Five years later, Anissa was free of cancer.¹⁴³ In an interview with CNN, Marissa explained "I saved her life."¹⁴⁴

D. *Parents' Right to Choose Donation*

An issue that clouds discussion of anencephalic organ donation is whether donation is the parents' choice. If the parents of an accident victim may choose to donate their child's organs, why can the parents of an anencephalic infant not do the same? The legal answer is that there is a difference between a living child, which has the right to have its best interests protected by the state,¹⁴⁵ and a dead child, which belongs to its parents alone.¹⁴⁶ Parents do not own their living children, although they do have constitutional rights to make decisions for them.¹⁴⁷ The parental right to make decisions for one's children stops short of actions which endanger the child in question.¹⁴⁸ Just as a parent may not risk a child's life, the parent also should not have an unfettered right to use the child

cult underlying issue: when is it acceptable to look at a baby as a source for organs rather than as a valuable person in its own right? Presumably, everyone would agree that it would not be permissible for parents to create a clone and then end the ensuing baby's life by taking an essential organ, regardless of another child's need for that organ. This stems from the fundamental principle that one life should not be taken just to save another.

141. Toufexis, *supra* note 140, at 56.

142. See Claudia Glenn Dowling, *Miraculous Babies*, LIFE, Dec. 1993, at 75, 75.

143. See Robert Jablon, *Miracle Gift Lasts 5th Year; Baby Conceived to Give Own Sister Marrow Transplant*, ROCKY MOUNTAIN NEWS, June 16, 1996, at 6A.

144. (CNN television broadcast, June 9, 1996).

145. See *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944) ("[T]he family itself is not beyond regulation in the public interest . . . [a]nd neither rights of religion nor rights of parenthood are beyond limitation.").

146. For example, Connecticut statutes provide that "the custody and control of the remains of deceased residents of this State shall belong to the . . . next of kin." CONN. GEN. STAT. § 45a-318 (1997).

147. See *Santosky v. Kramer*, 455 U.S. 745, 753 (1982) (noting a historical recognition of freedom of choice in family matters).

148. See *Custody of a Minor*, 393 N.E.2d 836 (Mass. 1979) (requiring standard medical treatment despite parents' wishes to rely on vitamin therapy). But see *In re Hofbauer*, 393 N.E.2d 1009 (N.Y. 1979) (allowing parents to treat cancer with nutritional therapy).

as an organ donor.¹⁴⁹

The debate over anencephalic organ donation takes place in the context of a fierce desire by some parents of dying children to have their children serve as organ donors. For example, a father of a seven year-old boy killed in an accident explained his feeling that knowing the boy's "organs live on in someone else is [like] an extension of his life that has made his death somewhat more bearable."¹⁵⁰ Such sentiments are hardly discouraged by doctors and hospitals that perform transplants.¹⁵¹ In fact, parents often see organ donation as a positive aspect of what would otherwise be unmitigated tragedy: the untimely death of a loved one.

This desire on the part of parents has led to reported cases of organ donation by anencephalic infants. For instance, recently an anencephalic baby, Baby Gabriel, was delivered at term despite her parent's knowledge of her condition.¹⁵² Shortly after birth, she was pronounced dead and transferred to Loma Linda University Medical Center in Los Angeles. When the doctors determined that Baby Gabriel had no chance of ever breathing on her own, she was removed from a ventilator and her heart was successfully transplanted to a critically ill infant, Baby Paul, who had hypoplastic left heart syndrome.¹⁵³

Following the Baby Gabriel transplant, Loma Linda suspended its program to harvest donor organs from anencephalic infants because of a lack of public consensus regarding when these infants can be deemed dead.¹⁵⁴ Dr. Leonard Bailey, the infant heart surgeon at Loma Linda, stressed that the program was only interested in anencephalic infants who could be declared brain dead. He ex-

149. See *Prince*, 321 U.S. at 170 (explaining that parents are free to martyr themselves, but that they are not free "to make martyrs of their children before they have reached the age of full and legal discretion").

150. Elisabeth Rosenthal, *Parents Find Solace in Donating Organs*, N.Y. TIMES, May 11, 1993, at C1. Voicing a similar perspective, a mother of a nineteen year-old killed in a riding accident said "I wanted some good to come out of it. It seemed morally wrong to bury those organs when somebody else could use them." *Id.*

151. For example, Dr. Jonathan Slater, a child psychiatrist associated with the pediatric cardiac transplantation team at Columbia-Presbyterian Medical Center's Babies Hospital in New York, reports that "[d]onating doesn't lessen [the parents'] pain, but it can give them a tremendous sense of continuity—that the loss has not been for naught—and that can be very helpful." *Id.*

152. See Annas, *supra* note 16, at 36.

153. See Brandon, *supra* note 30, at 782 (citing Sandra Blakeslee, *Baby Without Brain Kept Alive to Give Heart*, N.Y. TIMES, Oct. 19, 1987, at A1); see also Annas, *supra* note 16, at 36.

154. See Shewmon et al., *supra* note 16, at 1773.

plained, "I am not wacko; I am part of humanity I would not take the heart out of anybody who is still breathing and moving and kicking around."¹⁵⁵ Baby Gabriel's mother reported afterward that she was "probably one of the proudest people around—to know another little human being is alive when you've lost your own child. It's like smiling through tears."¹⁵⁶

A parent's legal rights, though, are highly fact specific. Parents clearly have the right to dispose of their child's body as they wish once there is a declaration of death.¹⁵⁷ In practical terms, this means that the parents can donate, without restriction, the organs that can be harvested from a body after the termination of respiration and heartbeat, including corneas and heart valves.¹⁵⁸ The parents can also offer the dead body of their child for medical research.¹⁵⁹ The remaining and more difficult question concerns the donation of solid organs that must be retrieved while the body is still oxygenated.

E. *When May Organs Be Removed?*

Determining when organs may be removed is an important question because the removal before death, or at least preservation of certain organs, is medically necessary. The necessity arises because the process of dying involves deprivation of oxygen that, for the most part, renders the organs unusable.¹⁶⁰ Thus, there is a special sense of urgency when the patient is a potential organ donor. As one doctor explains, "to wait for [the anencephalic infant] to die in the traditional way—cardiorespiratory arrest—would render his organs useless."¹⁶¹ After traditional death, the organs would be

155. Robert Steinbrook, *Doctors Seek Means of Using Babies' Organs*, L.A. TIMES, Nov. 12, 1987, Pt. 1, at 3.

156. Chartrand, *supra* note 7.

157. See, e.g., CONN. GEN. STAT. § 45a-318 (1997) ("[T]he custody and control of the remains of deceased residents of this State belong to the . . . next of kin.").

158. See *id.*

159. See *id.*; see also UNIF. ANATOMICAL GIFT ACT § 3, 8A U.L.A. 40 (1993) (defining who can make anatomical gifts of a decedent's body).

160. Cf. D.C. CODE ANN. § 2.1509.1 (Supp. 1998) (allowing techniques that preserve organs to be employed by hospitals prior to actually obtaining consent to donate). The *New York Times* has reported the following: "In Illinois, under a protocol developed by the Regional Organ Bank of Illinois, . . . [w]hen a person dies in an emergency room or is dead on arrival, doctors may infuse a cold preserving fluid into the cadaver's abdomen. Later, they will ask the family members for permission to take the organs." Gina Kolata, *Organ Shortage Leads to Nontraditional Transplants, and Ethical Concerns*, N.Y. TIMES, June 2, 1993, at A15.

161. Fost, *supra* note 12, at 333.

rendered useless because the natural suffocation that follows the cessation of breathing in an anencephalic infant whose heart stops beating makes harvesting the organs impossible.

However, there is a rule, commonly known as the "dead donor" rule, which states that a person must meet legal standards of death before donating organs. Under the dead donor rule, if the donor is still alive, his organs cannot be taken.¹⁶² Thus, the rule requires a diagnosis of brain death before organs can be donated. This, however, may render several organs of an anencephalic infant useless for purposes of organ donation. Therefore, several approaches for redefining the standard of death have been articulated; those approaches have been summarized by Dr. Norman Fost as follows: (1) waiting for cardio-respiratory death; (2) waiting a predetermined amount of time before declaring brain death; (3) redefining brain death as cortical death; (4) creating a separate category of brain death, based on a diagnosis of anencephaly; or (5) abandoning the dead donor rule entirely and allowing donations of vital organs from living persons.¹⁶³ The following subsections discuss the potential effectiveness of each of the proposed new standards of death.

1. Waiting for Death by Cardio-Respiratory Arrest

The first approach to reconciling legal standards of death with anencephalic organ donation entails waiting for traditional death by cardio-respiratory arrest and allows for a very clear demarcation between life and death. However, after waiting for traditional death, the heart and liver will be unusable due to the loss of oxygen perfusion.¹⁶⁴ Therefore, waiting for traditional death will not increase the number of organs available for donation.

2. Waiting a Predetermined Amount of Time Before Declaring Brain Death

The second approach set forth by Dr. Fost for reconciling legal standards of death with anencephalic organ donation requires waiting a predetermined amount of time for brain death.¹⁶⁵ However,

162. *See id.* at 332-33. The root of the dilemma rests on the words "still alive." If the issue were only the removal, or "harvesting" (the medical euphemism) of organs from a dead body then there would be few legal difficulties. The parents of an anencephalic infant could give such permission with no interference from the state.

163. *See id.* at 333-36.

164. *See id.* at 333.

165. *See id.*

waiting this predetermined amount of time raises many practical problems. Leaving aside the special issues raised by anencephaly, the entire subject of declaring an infant brain dead by any medical standard is a complex one. As Dr. Carol Leicher, a pediatric neurologist, explains, "no one has successfully devised a definition for declaring brain death for neonates."¹⁶⁶ This lack of definition likely stems from the fact that infants may later develop brain functions that they do not have at birth.¹⁶⁷ Based on this phenomenon, the Task Force for the Determination of Brain Death in Children has published standards that call for a waiting period of seven days after birth before declaring a newborn child to be brain dead.¹⁶⁸

For an anencephalic infant born with brain stem reflexes,¹⁶⁹ the policy promulgated by the Task Force would require at least a seven day waiting period while the baby is observed for signs of brain activity. This waiting period creates burdensome practical issues in the neonatal intensive care unit. The parents may choose at any time to withdraw life support and allow the child to die if they believe that the burdens of treatment outweigh the benefits to the baby. If, however, the baby is a potential organ donor, it must be kept on life support equipment for a full seven days before it can be declared dead.¹⁷⁰

Presumably, the anencephalic infant would be maintained on a respirator and other life-support equipment for the full seven days. Yet, there is no guarantee, or even a great likelihood, that an

166. Interview with Carol Leicher, M.D., Associate Professor of Pediatrics and Neurology, University of Connecticut School of Medicine, in Hartford, Conn. (June 30, 1996).

167. See Joseph J. Volpe, *Brain Death Determination in the Newborn*, 80 *PEDIATRICS* 293, 294-95 (1987).

168. See Task Force for the Determination of Brain Death in Children, *Guidelines for the Determination of Brain Death in Children*, 37 *NEUROLOGY* 1077, 1077-78 (1987).

169. There are at least 14 recognized signs of brain stem activity ranging from spontaneous respiration to a gag reflex. See Paul A. Byrne & Richard G. Nilges, *The Brain Stem in Brain Death: A Critical Review*, 9 *ISSUES IN L. & MED.* 3, 9-12 (1993). One test to determine brain death is a brain electrical activity, an EEG; however, in an anencephalic infant it is not useful because it measures higher brain activity, not brain stem activity. See *id.* at 14.

170. See Task Force for the Determination of Brain Death in Children, *supra* note 168, at 1077-78. As one commentator notes,

"only in the small minority of cases are questions concerning termination of life support or decisions to terminate such support made on the basis of a diagnosis of brain death. Indeed, most commonly, decisions concerning the termination of life support are formulated on the basis of the best interests of the devastatingly ill infant."

Volpe, *supra* note 167, at 296-97.

anencephalic infant will be any closer to a legal standard of death after seven days.¹⁷¹ The infant may still have some brain stem functions that prevent a declaration of death under the current, "whole brain death" standard.¹⁷² Also, during the waiting period, the infant would most likely have to be repeatedly resuscitated.

Recognizing this problem, parents of anencephalic infants seek to have their children declared dead at or before birth so that organs may be obtained. In a procedure that has become routine in harvesting organs from accident victims, a declaration of brain death allows the body to be supported by "life support" machinery that keeps the heart beating and lungs pumping.¹⁷³ Thus, the organs are kept viable until removed, at which point the machines are turned off.¹⁷⁴

3. Redefining Brain Death as Cortical Death

The third approach to reconciling legal standards of death with anencephalic infant organ donation would require redefining brain

171. Interview with Carol Leicher, M.D., Associate Professor of Pediatrics and Neurology, University of Connecticut School of Medicine, in Hartford, Conn. (June 30, 1996).

172. See *supra* notes 10-11 and accompanying text for a discussion of the "whole brain death" standard.

173. An article in the *New York Times* describes one family's experience as follows:

After Mark Flanagan had been declared brain dead and his parents had consented to donate his organs . . . the Flanagans stayed with Mark, who was still on life support but officially dead, placing blankets on his body "to keep him warm and help preserve the organs." Five hours later recipients were waiting, and surgeons were poised to operate. "Those hours were a peaceful time with him," said Mrs. Flanagan. "But it was very difficult seeing him wheeled off, then the doors close, then that's it."

Rosenthal, *supra* note 150.

174. See Kolata, *supra* note 160. The University of Pittsburgh Medical Center has developed a protocol which begins

when a person who is being kept alive on a respirator asks that the respirator be turned off and that his or her organs be removed for transplanting. The patient is [then] weaned from the respirator in an operating room, with surgeons standing by to remove the organs two minutes after the heart stops.

Id. This practice has been criticized by Dr. Renee Fox, a University of Pennsylvania sociologist, who commented that

she was appalled not only by "this almost desecrated death but also by the almost predatory degree to which we are trying to get organs." She also questions the idea of a timed death "in a freezing cold operating room, in the interior of a hospital, totally removed from friends and family and from anyone who had taken care of one."

Id.

death as cortical death.¹⁷⁵ This redefinition would designate anencephalic infants dead, even if born breathing, because they lack higher, cortical, brain function.

The strongest argument against changing the definition of death from "whole brain death" to "cortical" death, which would result in an exception for anencephalic infants, is that this redefinition could lead to further efforts at harvesting organs from people who are not now considered dead. Changing the law to make it easier to obtain organs from anencephalic infants could be the first step, however, down a slippery slope of obtaining organs from others in similar situations. This could include other people without consciousness, most notably those in a permanent vegetative state. In fact, the category could be expanded to include people who are conscious but have very short life expectancies, such as babies with fatal defects. Even more troublesome is the possibility of expanding the definition to include those with consciousness and a normal life expectancy, but who will always be severely impaired and unable to take care of themselves; this might include the mentally or physically handicapped. The slippery slope implications of changing the definition of death buttress the fervent opposition to anencephalic organ donation by groups that oppose it, such as the National Right to Life Committee and commentators who are troubled by the implication of the change.¹⁷⁶

Further, there is tangible evidence to support the concerns of the slippery slope. For instance, it is chilling to hear that surgeons in West Germany report removing the kidneys of an anencephalic infant before brain death without any legal ramifications.¹⁷⁷ In addition, Dr. Joyce Peabody, the chief of neonatology at Loma Linda Hospital, reported that during the time Loma Linda was seeking anencephalic infants as sources of organ transplants, she received a number of referrals from doctors of patients who did not have anencephaly.¹⁷⁸ Instead, they had other impairments; for instance,

175. See Fost, *supra* note 12, at 334-35 (focusing on loss of higher brain functions rather than all brain function as a standard of death).

176. The National Right to Life Committee has expressed a strong opposition to anencephalic organ donation. They write that "[b]asing 'personhood' on cognitive ability—abhorrent enough when applied to anencephalic infants—will inevitably be applied to others." Leslie Bond & Dave Andrusko, *Harvesting the Living*, in *A PASSION FOR JUSTICE: A PRO-LIFE REVIEW OF 1987 AND A LOOK AHEAD TO 1988*, at 83, 95 (Dave Andrusko ed. 1988); see also J.C. Willkie & David Andrusko, *Personhood Redux*, *HASTINGS CENTER REP.*, Oct.-Nov. 1988, at 30-33.

177. See generally Holzgreve et al., *supra* note 63.

178. See Shewmon et al., *supra* note 16, at 1775.

a neurologically intact baby born without kidneys. Describing these referrals, Dr. Peabody reported, "I have become educated by the experience. . . . The slippery slope is real."¹⁷⁹

4. Creating a Separate Category of Brain Death Based on a Diagnosis of Anencephaly

The fourth approach to reconciling legal standards of death with anencephalic infant organ donation would create a separate category of brain death for anencephalic infants.¹⁸⁰ Thus, an infant diagnosed with anencephaly would be legally dead. This proposal puts great importance on diagnosis, since the diagnosis of anencephaly would be an automatic declaration of death. This is troublesome, as there are a range of neurological impairments that fall short of true anencephaly, and a declaration of death would depend on the diagnostic skills of the attending physician.¹⁸¹

5. Abandoning the Dead Donor Rule Entirely

The final approach to reconciling legal standards of death with anencephalic infant organ donation imagines abandoning the dead donor rule altogether, thus permitting donation from anencephalic infants and persons in permanent vegetative states.¹⁸² However, some argue that loosening standards for organ procurement would cause a loss of public confidence in the entire organ donation process.¹⁸³

VI. APPLICATION OF ETHICAL THEORY TO ORGAN DONATION BY ANENCEPHALIC INFANTS

Ethical theory plays a significant role in the actions of a hospital team following a diagnosis of anencephaly. There is a well developed body of philosophy concerning the ethical obligations of health professionals.¹⁸⁴ As Dr. Melvin Lewis concluded in an important discussion of a case involving organ donation between twins, "[i]n an absolute sense, no one can ever know what is ulti-

179. *Id.* (alteration in original).

180. *See* Fost, *supra* note 12, at 334.

181. *See id.* at 335.

182. *See id.*

183. *See* CEJA, *supra* note 68, at 1617.

184. *See* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 7 (4th ed. 1994) ("Health care professions typically specify and enforce obligations, thereby seeking to ensure that persons who enter into relationships with their members will find them competent and trustworthy.").

mately the right choice: we simply cannot forecast the future.”¹⁸⁵ Most likely, the ethical issues surrounding organ donation by anencephalic infants will have to be discussed by hospital ethics committees. The following sections highlight a number of ethical theories that may be relevant to such discussions.

A. *Bioethical Theory*

As described by Tom Beauchamp and James Childress in their leading book entitled *Principles of Biomedical Ethics*, “ethical theory can illuminate problems in health care” by clarifying the relationship between what we do and what we think is the right thing to do.¹⁸⁶ The issue of anencephalic organ donation can be analyzed according to Beauchamp and Childress’ four cardinal principles of bioethical theory: autonomy, justice, nonmaleficence, and beneficence.¹⁸⁷

1. Autonomy

Autonomy involves respecting a “person’s right to hold views, to make choices, and to take actions based on personal values and beliefs.”¹⁸⁸ This stems from Immanuel Kant’s argument that each person must have “the capacity to determine his or her own destiny.”¹⁸⁹ When the individual in question is not competent to make his or her own decisions, Beauchamp and Childress recognize a hierarchy of three standards for surrogate decision making.¹⁹⁰ These three standards are as follows: pure autonomy, substituted judgment, and decisions based on the patient’s best interests.¹⁹¹ Since pure autonomy is based on respecting a patient’s previously expressed wishes, only the substituted judgment and best interests analyses are relevant in the case of an anencephalic infant who has never been conscious and could not have expressed any wishes.

185. Lewis, *supra* note 139, at 235. Discussing the psychological issues raised by using a seven year-old girl as a kidney donor for her identical twin, Dr. Lewis came to the conclusion that in the case of this particular child, “[h]er cognitive and emotional development, including her reality testing, were such that she did not appear to be in danger of experiencing the operation as an overwhelming threat.” *Id.* at 234.

186. BEAUCHAMP & CHILDRESS, *supra* note 184, at 3.

187. See generally BEAUCHAMP & CHILDRESS, *supra* note 184.

188. *Id.* at 125.

189. *Id.*

190. See *id.* at 170-81.

191. See *id.*; see also RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT (1986) (providing greater depth into the analysis of autonomy).

The second standard, substituted judgment, requires the decision maker to "make the decision the incompetent would have made if competent."¹⁹² Since the substituted judgment standard also presumes some former level of decision-making ability, it "cannot meaningfully be applied in cases where the incompetent person was never (or has not yet been) capable of making judgments or expressing wishes of his own."¹⁹³ Accordingly, having ruled out the pure autonomy and substituted judgment standard, only the best interests standard remains. The best interests standard takes the decision away from the patient and gives the surrogate authority to make a decision in the best interests of the patient.¹⁹⁴ The patient's best interests criteria is, therefore, the relevant model to look at when parents make decisions for their anencephalic child.

Another question that arises when the patient is an infant is whose autonomy is being infringed, the infant's or the parent's? If the answer is the parent's autonomy, then allowing donation will satisfy the parent's right to choose on behalf of his or her child. The parent's right to choose becomes clouded when the parent's choice causes death.¹⁹⁵ Still, parents are allowed to make choices for their severely ill infants, which result in the child's death. In cooperation with the doctors' medical judgment, a parent is allowed to decide that the burden of further treatment would not justify the benefit to the baby. Upon making this decision, the parent can direct that the child either be removed from life support equipment or not be resuscitated if he stops breathing.¹⁹⁶

However, if the infant's autonomy is to take precedence over the parent's autonomy, then many issues surface. Can an infant who has never had consciousness have the right to autonomy? Can his interests be separated from his parents? Does he have an inter-

192. BEAUCHAMP & CHILDRESS, *supra* note 184, at 171.

193. Ruth Macklin, *Return to the Best Interests of the Child*, in *WHO SPEAKS FOR THE CHILD: THE PROBLEMS OF PROXY CONSENT* 265, 290 (Willard Gaylin & Ruth Macklin eds., 1982).

194. See BEAUCHAMP & CHILDRESS, *supra* note 184, at 178.

195. If an anencephalic infant is not dead, then the process of donating organs will be the cause of death. Alexander Morgan Capron, writing on the problem of anencephalic organ donation, notes "an anencephalic neonate whose heart and lungs are functioning independently can not be considered brain dead. Indeed the baby lives." Alexander Morgan Capron, *Anencephalic Donors: Separating the Dead from the Dying*, HASTINGS CENTER REP., Feb. 1987, at 5, 5.

196. Taking another view, Arthur Caplan argues that the status of brain death is clearest in the case of an anencephalic infant where there is no higher brain function. See Arthur L. Caplan, *Should Fetuses or Infants Be Utilized as Organ Donors?*, 1 BIOETHICS 119, 122 (1987).

est in dying through the natural cessation of whatever brain function he has left, rather than through the artificial process of organ donation? Might not an infant, if allowed to choose, prefer to die as a result of donating his organs? This question is less clear when we consider that this is not a choice available to any person, conscious or not. When a person has suffered the complete cessation of brain function, he is dead by all legal and medical standards. If that person then goes on to become an organ donor, it is an act that has occurred after his death and does not cause death itself. No one is allowed, either through advanced directives or through reliance on substituted judgment, to sacrifice his own life for the purpose of donating organs. If such a possibility were open, we might well imagine that people would choose this option in advance should they ever be in a permanent vegetative state. In fact, this option is not available.

2. Justice

Beauchamp and Childress describe justice as "distributive justice," which is the "fair, equitable, and appropriate distribution in society determined by justified norms that structure the terms of social cooperation."¹⁹⁷ John Rawls, a leading contemporary philosopher of justice, views justice as fairness.¹⁹⁸ In determining whether justice is satisfied, we must ask if the result is fair. Are like cases being treated equally?¹⁹⁹ Justice is particularly relevant in a discussion of anencephalic organ donation. From the neurologist's point of view, the perspective of justice raises the greatest barrier to anencephalic organ donation. According to pediatric neurologist Dr. Carol Leicher, an anencephalic infant with a functioning brain stem is in exactly the same situation as a person in a permanent vegetative state who retains brain stem reflexes.²⁰⁰ Neither has satisfied the requirements for whole brain death, which is the currently accepted legal and medical standard for a declaration of death.²⁰¹

197. BEAUCHAMP & CHILDRESS, *supra* note 184, at 327.

198. *See id.* at 340.

199. This is sometimes viewed as a matter of equality; however, a recent article by Madison Powers challenges this Rawlsian perspective. *See generally* Madison Powers, *Forget About Equality*, 61 KENNEDY INST. ETHICS J. 129 (1996).

200. Interview with Carol Leicher, M.D., Associate Professor of Pediatrics and Neurology, University of Connecticut School of Medicine, in Hartford, Conn. (June 30, 1996).

201. *See supra* notes 10-11 and accompanying text for a discussion of the "whole brain death" standard.

Is it, therefore, just to treat anencephalic infants differently from persons in permanent vegetative states?

3. Nonmaleficence

Nonmaleficence is the obligation of the medical profession not to harm its patients.²⁰² The health professional's primary obligation is to do no harm.²⁰³ Beauchamp and Childress explain that the obligation to do no harm supersedes any possible collateral good result of the harm.²⁰⁴ Nonmaleficence would seem, then, to forbid both withdrawing and withholding treatment and the taking of organs from a living person, regardless of the shortness of that person's life span or the good the organs will do.

In the case of an anencephalic infant who retains brain stem function, removal of organs would directly cause the infant's death. Thus, harm would be done to the infant. Nonmaleficence, however, does not mean that every measure must be taken to prolong a patient's life, regardless of the consequences. Providing life sustaining care might harm a patient who has no prospect of surviving his sickness. Beauchamp and Childress point out that, in some cases, efforts made to preserve life actually cause suffering.²⁰⁵ How can a standard based on pain and suffering be applied to an anencephalic infant who presumably lacks the mental function to feel pain or to suffer? One answer, addressing the core of the most troubling issues regarding anencephalic infants, is that, as humans, anencephalic infants are entitled to the respect owed to all human life forms. The question can then be asked whether treatment is interfering with whatever quality of life the baby might experience, for example, being held by her parents as she dies.

4. Beneficence

Beneficence addresses the moral obligation in a health care setting to contribute to the patient's welfare.²⁰⁶ Many would argue that organ donation is the ultimate expression of beneficence. However, beneficence does not sanction doing harm to one person for another's good.²⁰⁷ For an act to be beneficent, it must also benefit, or at least have neutral consequences, for the patient. Harvest-

202. See BEAUCHAMP & CHILDRESS, *supra* note 184, at 189.

203. See *id.*

204. See *id.* at 191.

205. See *id.* at 233.

206. See *id.* at 259.

207. See *id.* at 266.

ing the organs of a patient not yet brain dead would not satisfy the requirements of beneficence.

Indeed, analyzing any individual's duty of beneficence to another, a precondition of any obligation is the principle that the "action would not present significant risks, costs, or burdens" to the giver.²⁰⁸ In the case of organ donation before complete cessation of brain function, the consequence to the patient/donor is death. Beneficence has never been used to justify a situation in which one person dies for the benefit of another. While no one can stop a person from giving his life for another in an emergency, in a medical setting, such beneficence would not be permitted. Parents could not, for example, donate their own heart to their child in need of a transplant.

A definitive change in law or public policy that accepts a less than "whole brain death" standard would likely affect both the beneficence and nonmaleficence principles. For example, there are viewpoints that receiving a blood transfusion is doing an extreme harm. Jehovahs Witnesses, for example, believe that receiving a blood transfusion makes it impossible for them or their families to enter heaven.²⁰⁹ Equally, there are those who believe that removal of organs, even after death, causes harm. At the same time, these are not universally held beliefs. These beliefs are reflected in current law by making receipt of medical treatment and donation of organs voluntary. Those who do not want to receive a blood transfusion or be an organ donor are not required to do so. Yet, there is no such option in the case of the "whole brain death" standard. One cannot opt in or out of "whole brain death." It is questionable whether the analogy to blood transfusions really holds. In the strict sense, people are not declared brain dead according to their beliefs. Less formally, however, a declaration of brain death is only made when the patient is a potential organ donor. If, for religious or other personal reasons, a patient does not wish to be an organ donor, it is unlikely that the medical staff will take the step of declaring him brain dead.

B. *The Virtues*

Another ethical theory which may shape the decisions of ethics

208. *Id.*

209. See James E. Dougherty, *Coronary Stent Placement as a Bridge to Coronary Artery Bypass Surgery in an Unstable, Anemic Jehovah's Witness Patient: A Case Report and Review of Bloodless Surgery Techniques*, 61 CONN. MED. 195, 197 (1997).

committees confronted with an anencephalic infant organ donation scenario is that of "virtues." The theory of "virtues" developed from Aristotle's principle of "arete," by which he meant the highest form of doing an action. For Aristotle, virtue constituted not just the act performed, but the state of mind of the person doing it. This theory of virtue was expanded by St. Augustine, who identified the cardinal virtues of prudence, courage, temperance, and justice. The concept of the state of mind of the actor, his virtue, in regards to medical decision making, was carried further by the major modern proponents of this theory, Edmund Pellegrino and David Thomasma in their book entitled *The Virtues in Medical Practice*.²¹⁰

Explaining the need for consideration of the virtues in medical decision making, Pellegrino and Thomasma write that principlism, the consideration of autonomy, justice, beneficence, and nonmaleficence, "fails to take into sufficient account of the character of the agent, as well as the nuances of real life that situate and define the moral quandary."²¹¹ For Pellegrino and Thomasma, it is not enough that the medical professional makes the right decision, but whether the decision is made for the right reason. For example, a physician may respect a patient's wishes when they are in concert with his own, but not when the physician disagrees with the patient. Disrespect by a physician of a patient's wishes, simply because he disagrees with the wishes, does not provide genuine respect for autonomy because the practitioner does not respect the patient as an individual.²¹² For many people, the idea of causing an infant's death, either by not resuscitating her or by removing her organs in order to save another infant, is the sort of "wartime triage" that a doctor of good character should guard against. However, Pellegrino and Thomasma recognize that there are some situations in which there is no common idea of good.²¹³ In those cases, "[a] moral decision is not a decision about a principle, but about the

210. EDMUND D. PELLEGRINO & DAVID C. THOMASMA, *THE VIRTUES IN MEDICAL PRACTICE* (1993). For another discussion of virtues, see ALASDAIR MACINTYRE, *AFTER VIRTUE* (2d ed. 1984).

211. PELLEGRINO & THOMASMA, *supra* note 210, at 101.

212. Pellegrino and Thomasma stress that attention to ethics and principles does not guarantee a good result. For example, in writing about the abuses by doctors during the holocaust they note that "the lessons to be learned from this experience are that all individuals must be treated as ends in themselves, that the evils of wartime triage should not become ordinary or accepted ethical practice." *Id.* at 15. They further write that "only critically reflective medical ethics and self-critical individuals of good character can offer some hope that history will not be repeated here." *Id.*

213. *See id.* at 18.

relationship of circumstances, intentions, and ends to a principle.”²¹⁴ Thus, a virtuous physician does not only “what is required as duty but seek[s] the perfection—the excellence, the *arete* of a particular virtue.”²¹⁵ The virtuous person is therefore impelled by his virtues to strive for perfection.²¹⁶ Striving for perfection contrasts with settling for an adequate or acceptable result.

Using virtues such as justice and courage, an individual medical practitioner must consult his own conscience when deciding whether to prolong an anencephalic infant’s life.²¹⁷ Regarding anencephalic organ donation, a virtues based analysis would conclude that the life of an anencephalic infant should have no less value than the life of a healthy infant either because the infant lacks consciousness or because of the great good that the anencephalic’s organs can do for another infant. The physician should seek moral excellence in the care of his patient; he should not seek to achieve the best result for society.

C. *Consequentialism*

As a moral theory, the ethics of the virtues analysis stands opposed to a consequentialist perspective which calls for performing the act that will do the most good over all.²¹⁸ A consequentialist looks to the benefit to society, perhaps in the form of making resources available to others through the withholding of treatment from an anencephalic infant. The question asked by the consequentialist is whether an anencephalic’s organs would help an otherwise healthy baby who will die without an organ transplant. In other words, the actual morality of an act, in this case ending the life of a baby, can, under a consequentialist view, be weighed against the good that act will create. Few members of hospital ethics committees are strict consequentialists. However, it is important for this theory to be recognized so that everyone involved can fully understand the implications of acting or not acting.

214. *Id.* at 23.

215. *Id.* at 166.

216. *See id.*

217. For Pellegrino and Thomasma, this would result in a decision not to sacrifice the life of an anencephalic infant even for the purpose of saving other children. Quoting Joseph Cardinal Bernardin’s address on euthanasia at the University of Chicago Hospital they write “[w]e cannot accept a policy that would open the door to euthanasia by creating categories of patients whose lives can be considered of no value merely because they are not conscious.” *Id.* at 122.

218. *See generally* SHELLY KAGAN, *THE LIMITS OF MORALITY* (1989).

D. *Communitarian Bioethics*

Communitarian bioethics, another popular theory, is centered on the patient's own values. Therefore, communitarian bioethics is difficult to apply in the case of an unconscious patient. As explained by Drs. Ezekial and Linda Emanuel, the ideal relationship for a patient and physician is a deliberative model in which the doctor acts as a teacher and a friend to the patient.²¹⁹ In contrast to a paternalistic model, in which the doctor does what he thinks is best, and an informative model, in which the doctor merely provides information, in the deliberative model the physician helps the patient identify "the best health related values that can be realized in the clinical situation."²²⁰ In a deliberative model, the patient's own values are open to discussion in a manner that promotes self-understanding relevant to medical care.²²¹

Yet, how can an anencephalic infant's physician work in a deliberative model? The patient is not only unconscious, but has never been conscious. As with the other theories, the doctor pursuing a deliberative model must work with the infant's parents, who are the infant's representatives. The physician cannot, however, forget that the infant is his patient, not the parents. It may be acceptable to the physician to abide by the parents' decision to withdraw or withhold life support if the burdens of treatment to the patient outweigh the potential benefits. Such an agreement would not necessarily include taking organs from a breathing, though unconscious patient, regardless of the potential good this act would do for others.

E. *A Philosopher's Analysis of Anencephalic Organ Donation:* *Hans Jonas*

In the event that there is time for a full exploration of ethical issues, the ethics committee would benefit from reading two important essays by the philosopher Hans Jonas. These essays explore issues of declaring brain death for the purpose of organ donation.

There are two Jonas essays that are relevant to anencephalic organ donation: *Philosophical Reflections on Experimenting with Human Subjects* and *Against the Stream: Comments on the Defini-*

219. See Ezekiel J. Emanuel & Linda L. Emanuel, *Four Models of the Physician-Patient Relationship*, 267 JAMA 2221, 2222 (1992).

220. *Id.*

221. See *id.* at 2222, 2225-26.

*tion and Redefinition of Death.*²²² In these two essays, Jonas considered, not anencephalic neonates in particular, but subjects of human experimentation and brain dead organ donors. These two subjects raised issues highly relevant to anencephalic organ donation: the pronouncement of death and the exploitation of the powerless.

Writing *Philosophical Reflections* at the time of the Harvard Ad Hoc Committee's report on the recognition of brain death,²²³ Jonas had no disagreement with the idea that a person whose heart and lungs were being maintained by machines might still be dead because of lack of brain activity.²²⁴ Jonas objected, however, to declaring brain death for the purpose of converting the patient into an organ donor. The doctors in this process want not permission "to turn off the respirator, but, on the contrary, to keep it on and thereby maintain the body in a state of what would have been 'life' by the older definition (but is only a 'simulacrum' of life by the new)—so as to get at his organs and tissues under the ideal conditions of what would previously have been 'vivisection.'"²²⁵ Jonas further argued that "[s]ince we do not know the exact border line between life and death, nothing less than the maximum definition of death will do—brain death plus heart death plus any other indication that may be pertinent—before final violence is allowed to be done."²²⁶

Addressing the issue a year later in *Against the Stream*, Jonas reaffirmed his distrust of the Harvard Committee's motives because of their bias toward obtaining organs for transplantation. Jonas supported his position by quoting the author of the committee's report, Dr. Henry K. Beecher, who asked "[c]an society afford to discard the tissues and organs of the hopelessly unconscious patient when they could be used to restore the otherwise hopelessly ill, but still salvageable individual?"²²⁷ Jonas replied, this "intrusion into the theoretical attempt to define death makes the attempt impure."²²⁸

Given Jonas' definitive views on the inability to know where

222. HANS JONAS, *PHILOSOPHICAL ESSAYS: FROM ANCIENT CREED TO TECHNOLOGICAL MAN* 105-40 (1974).

223. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 JAMA 337 (1968).

224. See JONAS, *supra* note 222, at 129-30.

225. *Id.* at 129.

226. *Id.* at 130 (emphasis omitted).

227. *Id.* at 133.

228. *Id.* (emphasis omitted).

the line is between life and death, he probably would have, had he considered the issue, opposed both the AMA and the legal proposal for harvesting organs from an anencephalic infant. Indeed, an anencephalic infant is the prototype of Jonas' unconscious, but not yet dead person. In responding to critics who described brain dead organ donors as vegetables, Jonas wrote "as if 'vegetable' were not an instance of life!"²²⁹ This echoes a recent comment by a leading ethicist that an anencephalic neonate is at the same brain level of a fish and therefore is an appropriate source of organs.²³⁰ Many would question whether a human baby, regardless of her medical condition, could be compared with a fish. Jonas would not find the comparison useful. Instead, he would ask whether we have trouble distinguishing a dead fish from a live one? If the fish is alive, do we not understand that by depriving it of oxygen we are killing it? A baby, even one with no higher brain function, is either alive or dead.

Some of Jonas' arguments may seem to favor anencephalic organ donation over other brain dead organ donors because the anencephalic has never been a living, feeling person. He writes that as long as the body "breathes [or] pulses . . . [it] must still be considered a residual continuance of the subject that loved and was loved, and as such is still entitled to some of the sacrosanctity accorded to such a subject by the laws of God and men."²³¹ Although the anencephalic never "loved," he "was loved" by his family. Does his lack of ability to feel emotion automatically make him a potential organ donor? Yet, Jonas' strong position against capitalizing on an unconscious being, regardless of the reason for his unconsciousness, weighs toward his opposing the use of anencephalic infants as organ donors.

Jonas argues persuasively that the greatest sacrifices should not be exacted from the most vulnerable. Writing on the use of human subjects in scientific experiments, Jonas stated "the poorer in knowledge, motivation, and freedom of decision (and that, alas, means the more readily available in terms of numbers and possible manipulation), the more sparingly and indeed reluctantly should the reservoir be used, and the more compelling must therefore become the countervailing justification."²³² The shortage of donor

229. *Id.* at 135.

230. *See* Chartrand, *supra* note 7.

231. JONAS, *supra* note 222, at 139.

232. *Id.* at 123.

organs would not, to Jonas, be a "countervailing justification." Harvesting organs from the unconscious patient is "simply and unqualifiedly impermissible; progress or not, he must never be used on the inflexible principle that utter helplessness demands utter protection."²³³

Jonas' clear repudiation of using unconscious persons as organ donors places him outside the mainstream of today's medical practices. Patients without brain activity who are not breathing on their own are often declared dead for the purposes of organ donation. A new refinement to this technique developed by the Pittsburgh Medical Center calls for withdrawing life-support, waiting two minutes, and then harvesting organs from the newly dead patient.²³⁴ Jonas would argue that both techniques unjustifiably interfere with the dying process and thus risk obtaining organs from living persons.

Jonas' work evidences his awareness of where this practice could lead. One instance concerns the slippery slope effect of using brain dead individuals as organ donors. Ironically, he writes of alternative uses for the breathing body that would be the corpse: "[l]et us not forget research. Why shouldn't the most wonderful surgical and grafting experiments be conducted on the complaisant subject-nonsubject . . . ? What a boon for medical instruction, for anatomical and physiological demonstration and practicing on so much better material than the inert cadavers otherwise serving in the dissection room!"²³⁵

Jonas' fears have become reality. In a recent article by a medical student present at the removal of organs from a young boy declared brain dead, the author writes that after the organs were removed "all that was left on the table was a carcass of a boy. My chief resident provided . . . me with one of the best anatomy lessons [I] had ever had. We saw muscles, nerves, and other structures that we had never found in our cadavers in anatomy class."²³⁶

Hans Jonas would approve of the AMA's reversal of its decision to use "living" anencephalic neonates as organ donors. His fears regarding the eventual result of an increasing practice of declaring terminally ill patients "brain dead" for the purposes of organ donation have come true. We have, to a large extent, become

233. *Id.* at 126.

234. See *supra* note 174 and accompanying text for a discussion of this practice.

235. JONAS, *supra* note 222, at 137.

236. Julie Rothstein, *Attending to Transitions: A Medical Student's Encounter with Transplantation*, MAKING THE ROUNDS IN HEALTH, FAITH, & ETHICS, Oct. 23, 1995, at 1, 5.

complacent with the process, enough so that many are willing to view a breathing, pulsing newborn infant as an appropriate organ donor.

VII. RECOMMENDATIONS

Viewed in light of current legal, public health, medical, social, and ethical norms, the anencephalic infant is viewed as having a catastrophic birth defect not compatible with life. Anencephalic infants are not suitable candidates for organ donation because they do not meet current legal or medical standards of brain death.²³⁷ Efforts to blur the distinction between life and death, by considering the relative value of an anencephalic infant's quality of life, are troubling. As the discussion of the slippery slope shows, it is a short distance between deciding that an anencephalic baby has no life worth living as compared to a person in a permanent vegetative state who lacks upper brain function.²³⁸ The danger surrounding anencephalic infants is that the prospect of donation is especially attractive because the ending of one life can have the direct result of preserving another life. Furthermore, the need to find meaning in the life of anencephalic babies makes organ donation by anencephalic infants a bitterly difficult problem.

Given the continued shortage of donor hearts,²³⁹ the issue of making more organs available continues to be pressing. Whether anencephalic infants can be a source of these organs remains a highly controversial legal, public health, medical, social, and ethical issue. Society as a whole should determine whether anencephalic infants are to be used as organ donors. As such, the issue requires more public understanding of the factors that lead some to see anencephalic infants as dead. More than a technicality or a legal obfuscation, the barriers to anencephalic organ donation are based on what we as a society are willing to call life and death.

Nevertheless, ethics committees and hospital counsel must continue to deny the wishes of parents who want their anencephalic infants to be organ donors, not based solely on a current interpretation of the law, but because our society believes it is important, as Capron said in 1987, to "separate the dead from the dying."²⁴⁰

Given the competing interests inherent in anencephalic organ

237. See Fost, *supra* note 12, at 333; see also *supra* Part IV.E.

238. See *supra* note 80 and accompanying text.

239. See Kinkopf-Zajac, *supra* note 26, at 521-23.

240. Capron, *supra* note 195, at 5.

donation, what should an ethics committee do? The best resolution of the issue starts with a clear understanding by the ethics committee itself, and the attending medical personnel, of what constitutes anencephaly and what surrounds anencephalic organ donation. The first hurdle is brain stem function. It is too easy to think of anencephalic infants as being "without" a brain and therefore not fully human. In fact, society is far from a definition of what being "fully human" entails and, until such a consensus is reached, we are left with the law as it now stands. The law in the United States recognizes only two states of being, alive and dead.²⁴¹ Death is defined in various ways, but in essence involves the complete absence of brain function.²⁴² While respiration and heart beat can be sustained by machines and drugs, making them less reliable indicators of life, there is currently no way to support brain activity.

A person who is dead, who has no brain function, may be a source for organ donation.²⁴³ That person must be declared dead by competent medical authorities based on the legal definition of death in the state. Thus, while the biomechanics of life can be sustained artificially until the actual moment when the organs are removed, the individual is dead at the time that death is declared. Death does not occur at organ removal.

At least for the time being, the law's answer to anencephalic organ donation is the correct one as well. Until much more is known about brain function, it seems unduly careless to extend the definition of death to include individuals with at least some brain function as dead. This is true for both the person in a permanent vegetative state as well as for the anencephalic. Whether the person never has, or never again will have, higher brain function does not speak to his condition at the moment. What is he now? Is he alive? The root issue with anencephalics and persons in persistent vegetative states may be that it is a judgment of lack of potential. This is a slippery slope that we should be very careful of sliding down as it has no natural hand-holds.

That the distinction between total brain death and near total brain death seems a fine one is not a reason for rejecting the distinction. The anencephalic organ donation programs that led to a variety of infants who were far short of anencephalic being proposed for organ donation evidences our general uncomfortableness

241. See *supra* Part V.

242. See *supra* Part V.

243. See *supra* Part V.E.

with this topic.²⁴⁴ It is important to remember that this decision is being made under the pressure of a shortage of donor organs.²⁴⁵ This same pressure likely caused the adoption of our current standards of brain death. If there were no need for organs, there would be no need to declare brain death. Instead, families could decide to withhold or withdraw treatment without influence of what is needed for the greater good. We are prepared to reason backwards when it comes to finding sources for donor organs because society sees organ donation as a good thing.

Writing this, I appreciate that nothing will convince parents like the Ms who have experienced the death of their baby without any possibility of mitigation through organ donation. To them I would say, the best resolution for an individual family is not the best resolution for society as a whole. If anencephalics may be organ donors, then why not persons in permanent vegetative states or persons with subnormal intelligence? Much of the tragedy of the Ms' decision was the lack of consistent information.²⁴⁶ If there is a well thought-out, clearly expressed position on anencephalic organ donation developed before the situation arises then parents of anencephalics will not be given false hopes or unrealistic expectations. An anencephalic infant's short life may be given meaning through methods short of organ donation. For instance, after they die, anencephalic infants can be used for research purposes in order to increase medical science's knowledge of the condition. Corneas and heart-valves, which remain useable after death,²⁴⁷ can be donated without restriction. Solely because a baby will die without ever having attained consciousness does not mean that the child is not, nor ever has been alive. Legal standards for organ donation have been set in the United States, and until there is a consensus that these standards should be changed, anencephalic infants cannot and should not be used as sources for donor organs.

EPILOGUE: THE MS

Speaking with the Ms eight months after the triplets' birth, it is obvious that they still feel anger and frustration at the events surrounding their attempts to donate baby Avery's organs. The Ms

244. See *supra* notes 178-79 and accompanying text (discussing proposals of donation by those with conditions other than anencephaly).

245. See *supra* Part II for a general discussion of the shortage of donor organs.

246. For a discussion of the Ms' experience, see the Prologue to this Article.

247. See Lafreniere & McGrath, *supra* note 14, at 445.

were very willing to talk about that time, and about their feelings then and now. Mr. M said talking about Baby Avery made him feel better. Mrs. M mourns both Baby Avery and her mother. She feels that Baby Avery is now with her mother and that her mother is taking care of her baby. Baby Avery is very much a presence in the Ms' home. They report having pictures of Baby Avery throughout their house. The Ms plan to tell the two surviving triplets the story of Baby Avery, including, when the triplets are older, the organ donation that never happened. At the one-year anniversary of Baby Avery's death, the Ms and their children released balloons into the sky for Baby Avery and for themselves. The children's balloons, reported Mrs. M, "all veered off to the left. Baby Avery's balloon," a big pink one, "went straight up to the sky."